University of Alberta

Hearing the Call of Parents: Relational Ethics in the NICU

by

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To Craig, Gabe and Sadie, with my love.

ABSTRACT

This inquiry is focused on revealing the moral nature of relationships between parents whose babies are hospitalized in the NICU and the health practitioners who care for them. This understanding is sought from the point of view of the parents using an Interpretive Descriptive research method (Thorne, Reimer Kirkham, & MacDonald-Emes, 1997) and through the analytical lens of relational ethics (Bergum & Dossetor, 2005). Four themes were evoked by the parents' descriptions of their experience: *walking into an alien world, being vulnerable; becoming vigilant, going home at night: trust in the NICU* and *coming face to face: please see me.* Relational autonomy is offered as a way toward being in relation for parents and practitioners. In conclusion, the importance of understanding these relationships as morally inhabited lies partly with the baby herself; the initial experiences of parenting can stay with the parents forever and contribute to the foundation of the parent child-relationship.

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CHAPTER ONE

Introduction and Significance of the Study

The NICU is rich territory for ethical dilemmas and decisions. It is inhabited by decisions concerning the limits of human viability, invasive procedures, end-of-life care, prolonged death and resuscitation. However, if these dilemma-inspiring situations can be thought of as moral mountains, then what I am interested in and curious about is the broader moral landscape of the NICU. The gazes, the touches, the movements of staff and parents together—my interest dwells on the moral character of these interactions. While it is difficult to imagine (and unrealistic to expect) ever describing the experience of having an ill or premature baby in intensive care as positive, the relationships between the parents and the care givers, particularly the nurses who remain at the bedside for eight or twelve-hour shifts, clearly influence the meaning, duration and outcome of the NICU stay for the parents. As an NICU nurse, I witnessed the difference that could be made in the experience of distraught parents of a child born months too soon when a nurse or physician sought to move toward them and share the encounter. These ethical instants happened moment by moment, not just when a major end-of-life or treatment decision had to be made. These moments did not involve the weighting and comparing of what was right and what was wrong, but seemed to be more centred on recognizing one another's humanity.

Ethical moments such as these may best be understood as questions. Questioning, itself, has an integral, fundamental role in postmodern ethics. Bergum (1999) has claimed that ethics in health care are "fundamentally a matter of questioning, which requires openness, deliberation, self-reflection, uncertainty and contemplation" (p.167). Questions are an important way to approach ethics because they invite dialogue. My questions include: Why were those parents who asked questions and wanted to stay at their baby's bedside all night called "difficult"? Why was primary nursing (the commitment to care for the same baby for the duration of his stay) embraced by some nurses, but rejected as "too difficult", "too demanding", "too emotional" by many? How did some nurses and physicians consistently make connections with the sick infant and her[1] parents? Why were others who were regarded as expert technical practitioners recognized by staff and parents as lacking "bedside manner" or "people skills"? How can we *be with* parents even when we do not know the right thing to do? Finding the right words to describe these experiences, this knowledge, is difficult. I recognized these relations when I saw them, or when I was immersed in one, and realized that there was something morally important demanded in the relationship between the patient and care giver; something that was beyond what might be captured by a rational argument for what is 'right', or that might be governed by ethical principles.

Sometimes, the abyss between parents of ill children and health care providers is wide. Carole Schroeder (1998), a nurse scholar whose second child was born with complex congenital heart anomalies, reports that well into her infant daughter's hospitalization, a "male neonatologist, tired of my constant presence and watchfulness, accused me of neglecting my son, saying 'Don't you have another child? You belong home taking care of him, not here. Leave this ill child to the experts!" (p. 4 of 8). Eventually, other mothers and health care providers did reach out and engage with Schroeder, enabling her to advocate for care that saved her daughter's life. Other parents have written of being so misunderstood, so apart from the experience of the health care providers, it is nearly impossible to imagine the gulf ever being breached.

In their book describing the hospitalization of their premature son, *The Long Dying of Baby Andrew,* Robert and Peggy Stinson (1983) compile their own journal entries written during Andrew's hospitalization, and intersperse them with excerpts of the medical record they obtained after Andrew's death. Nearly two months into the particularly difficult hospitalization following the birth of their son at 24-weeks gestation, Peggy's journal documents a meeting with two physicians to discuss Andrew's progress. After hearing what sounds to them like very little progress accompanied by much suffering, Peggy begins again to attempt a discussion about the morality of prolonging Andrew's pain and death. Finally, she and her husband explicitly ask if the time had come to reassess the wisdom of trying to keep Andrew alive. One physician (Craft) responds:

---

[1] To avoid the awkward wording that occurs when trying to represent both genders (e.g.*her or his*) and to reflect all NICU babies, I alternate her with his; girl with boy; she with he, etc. throughout the text. Except where clearly indicated, the use of a gender-specific pronoun refers to babies of both genders.

> "No," he said. He looked at me dully. "This is just a technical management problem."
>
> A *technical management problem.* This whole thing is tearing our lives apart, this crisis of the utmost medical-ethical-social-legal complexity, and to him it's "just a technical management problem." I started to cry.
>
> Craft took the initiative to break the silence this time. "Wouldn't you feel guilty if we did go ahead and turn off Andrew's respirator?"
>
> I thought I couldn't stand it anymore, this bland assumption that only one side could possibly be wrong, that only one side—me—should be feeling guilty. But I only looked at him in the eye for a change and said with all my accumulated bitterness, "The only thing I'll ever feel guilty about is signing Andrew into this hospital." (Stinson & Stinson, 1983, p.130).

This example is a poignant illustration of the need for research that seeks to understand the ethical relation between families and care providers in the NICU. It would be easy to assume that the main moral issue in *The Long Dying of Baby Andrew* revolves around a decision to discontinue life support and let Andrew die or aggressively treat Andrew to save his life at all costs. However, the above passage makes clear that there is no engagement, no turning to the other, between Andrew's parents and his physicians. So, if climbing the moral mountain here is akin to debating Andrew's right to life or a peaceful death, perhaps we can imagine the moral horizon so obscured by thistles and thick undergrowth, the landscape made so treacherous by ruts and gorges, this mountain cannot even by seen by all, much less approached and climbed. The view of each person is so entirely different, they cannot even get to the question: What is the right thing to do?

Relational ethics is a way of *doing* ethics that focuses on the relationships we have with other people. Austin, Bergum and Dossetor (2003) refer to it as an action ethic. It involves honouring the interdependence that the patient, client, or practitioner shares with other people—colleagues, relatives and friends within their environment. It calls for a consciousness and understanding of our own humanity, our own struggles and suffering so that we then can move to respond to the struggles and suffering of others. Here a mutual process of growth occurs as the practitioners' response to the suffering of others leads them to better recognize their own suffering which in turn helps them to better understand that of their patients (Bergum, 2004). This mutual nature is important; both the healthcare practitioner and patient have expectations and obligations, while recognizing the inherent power inequality that occurs when the patient is asking for help and the practitioner has promised to provide help. It is turning to the other person, recognizing that illness and healing have meaning in the lives of patients and their families. And if we do not know what this meaning is, we begin by at least recognizing that they mean something. Movement towards the other person, or engagement (Bergum, 2004), involves a genuine intention to understand the person before you and her perspective. It is understanding that when a first-time father leaves his wife lying in recovery to walk into the loud and bright NICU, with bells and alarms and equipment everywhere, to find his baby, born ill or too soon, that we are morally obligated to reach out to him, to recognize that what may be just another admission to us, is a monumentally life-changing event for him. It is accepting, also, that we might not know exactly how to do this and that every father may require a different approach, but that we must respond to the call of *this* father.

Purpose of the Study

The purpose of this study is to increase understanding of the moral relevance of relationships between parents of intensively ill babies and their health care providers. Relationship can exist in the glance between people, a touch, or in words spoken. The relationships I am curious about here are those that form between parents of ill babies in the NICU and the health care practitioners providing care to these families. I seek to 'reframe' and broaden the ethical discourse in the NICU to include not only those moral mountains of ethical dilemmas, but also to include acknowledgement of the need to tend the moral landscape of relationships. The framework for this study is relational ethics (Austin, Bergum & Dossetor, 2003; Bergum, 2004; Bergum & Dossetor, 2005). A further purpose of this study is to "apply" relational ethics as researched by Bergum and Dossetor to a clinical setting in order to further develop and enrich this approach to ethics.

Significance of the Study

I once was the primary care nurse for a baby, Caleb, who was born ten weeks early and small, about the size of someone born fourteen weeks early. His parents were interesting, loving, well-educated people who were generous and thoughtful towards their baby and the NICU staff. Caleb had a somewhat complicated course of illness and recovery related to his prematurity, including episodes of infection or suspected infection and difficulty making the transition to breathing on his own. By the time Caleb was well enough to move to a bedside in the less acute part of the nursery, his parents and I had a deeply trusting and committed relationship in the context of caring for Caleb and, at the point in time of this story, we had all acknowledged that the worst was over. One evening, I was working a night shift, his parents gave Caleb a bath, we completed the daily ritual of weighing him and his mother held him for a long time in the rocking chair. By now we knew each other well and had a pleasant, enjoyable time as I helped them and the other families in my assignment until it came time for them to go home for the night. His father said goodbye to Caleb and he and I chatted conversationally about how well Caleb was doing and other things. I noticed him glancing with concern at Caleb's mother saying goodbye and I turned to look at her.

She was turned toward us but we could not see her face; her forehead rested on the isolette as she gazed in at Caleb. She lifted her head to us and I saw that her eyes had tears in them. “It’s just so hard…” she said, in a voice just above a whisper. I immediately went to put my arm around her and shortly after they walked out of the unit arm in arm. I felt as if I had been shaken out of a sense of complacency and could not stop thinking about her all that night. How I had been laughing and chatting with Caleb’s father, anticipating a relaxed shift with stable, growing babies. How I had been feeling the happy satisfaction of completing the evening baths and the relief of Caleb’s much improved condition. And all that time, at the same time, her heart was breaking – breaking because they were leaving the unit without their baby – again. I spent the night realizing that I had assumed, without even realizing, that because Caleb was so much more stable, and doing so well, that their troubles, their worries, were over. It had not occurred to me that they were still so vulnerable because I had assumed, without even being aware of my own assumption, that their vulnerability was linked to the stability of their son’s illness. And I became acutely aware of how wrong I was.

Having a child in the NICU is a tangled mess of experiences and emotions, taking place in a structured, controlled and policy-bound setting. Even in relatively uncomplicated situations and with positive outcomes, what is often anticipated to be one of the most joyful times in our development as human beings, the birth of a baby, becomes mixed with sorrow, disappointment, fear and grief. This experience must be attended to with moral consideration and thoughtfulness, for often it is at these crossroads of our lives that human potential may be realized. To better understand this experience is to better understand the richness of our potential, in both its finest and darkest hour. The findings of this study contribute to increasing the sensitivity toward and understanding of the moral meaning and implications of relations between NICU parents and the people who provide them and their babies with health care.

In his account of the early birth of his twins at 24 weeks gestation, William Woodwell (2001) incorporates journal entries he wrote during the experience with his own retrospective analysis. At the point of the following entry, his wife, Kim, is in the hospital and has been diagnosed with severe preeclampsia. Although she feels well at present, she is being closely monitored and they have been told that as soon as her symptoms become serious, the babies will have to be delivered—months too soon. In this journal entry, Woodwell refers to the profound influence the words of health care providers have on the experience of patients and families:

> Wednesday, May 28, 2000: You start to understand the incredible power these people have over your emotions. First you're hearing you have days or just hours and then, all of a sudden, someone opens the door to a whole new possibility: your babies might indeed be born at twenty-eight weeks [Which, in this context, they perceive to be a positive outcome]. You are fast to embrace any statement, theory, or turn of phrase that sounds even remotely more optimistic than what you've heard before. I wonder if the doctors and nurses know—really know—how much we hang on their every word (brackets added, p.28).

CHAPTER TWO

Literature Review: What Do We Know?

Exploring the literature to ground and inform this study occurred along two different but connected paths. The search for literature occurred mainly on the Cinahl, 1982 to 2007; Pubmed; and Philosopher's Index, 1940 to 2007 databases. Except for classic articles (referenced by many of the later studies), I limited my search to articles published after 1990. Search terms included: NICU, parenting, mothering, fathering, ethics, family-provider relationships, engagement, and relational ethics. Additional articles were retrieved from reference lists of articles obtained through the literature search, and some other articles were found inadvertently, or on the recommendations of others aware of my research focus. As well, a general internet search was done using the Google search engine (accessed August 06, 2007) and the exact search term: "what is it like to be a parent in the NICU?" retrieved 272, 000 articles. A scan of these results indicated that most of these were items for parent teaching or advertisements for books, and did not contribute to the review.

Initially, the literature was broadly searched to provide an overview of research studies and theoretical and scholarly discussions describing the experience of parenting in the NICU, as well as first-hand accounts written by NICU parents. Not all of this literature specifically set out to describe or study parent-provider relationships however, the research studies often pointed to the influence of these relationships in their findings. The first person accounts of the parents included many rich descriptions of relationships with health care providers, particularly nurses and physicians, and how these relationships affected the parents' lives. A second search was also done focussing on the relationships between patients, families and health care providers, not necessarily set in the NICU. The final part of this review discusses specific research and scholarly works exploring relational ethics.

This literature review seeks to show what previous researchers and scholars have discovered about parents in the NICU. It demonstrates a need for research that reflects parents' experiences with healthcare providers in the NICU as disclosed by the parents, and revealed through the lens of relational ethics.

The Experience of NICU Parents

The many research and scholarly articles focusing on parents in the NICU indicate that there is much acknowledgment of and attention to their experience. One important caveat regarding this research is that the majority of authors concerning parenting in the NICU have focused on the experience of mothering. Studies focused on the experience of both parents together, or comparing parents appear more recently, however, still much less research exists on the experience of NICU fathers alone. Therefore, most of the conclusions drawn in terms of the literature are based primarily on mothering and the experiences of mothers. Another dichotomy occurs in the NICU literature referring to either premature babies, or ill term babies. NICUs admit both babies who are born too early and require support to finish developing and treat the associated medical problems; as well as those who are born at term with congenital illnesses or birth trauma. The NICU literature tends to focus more heavily on the issues of prematurity; however, since I have chosen to study parents of babies ill for any reason, both sets of references are included in this review.

The NICU Space

A first-year resident, having just become a father and following a four week rotation in the NICU, shares his impression in Swanson's (1990) phenomenological study of NICU care providers: "'It's a place where sort of all the hope that we often put in babies is…is very frustrated, and it's only in coming out of it that you can again have the perspective of hope again'" (p.60). This reference to a general societal expectation and picture of babies as hopeful is paralleled by the specific hopes and dreams individual parents feel towards the birth of their child. These hopes and dreams are challenged in a devastating way if one's own child is admitted to an NICU. The unit itself is an overwhelmingly physically, emotionally and intellectually stressful environment and a premature or ill term baby is considered a crisis (Gale & Franck, 1998; Shellabarger &

Thompson, 1993). In memoir, parents have described their first impressions of the NICU as bright, loud, crowded and scary (Owens, 2001; Woodwell, 2001).

Dobbins, Bohlig and Sutphen (1994) have suggested these environmental factors are direct barriers to parenting and in their survey of 207 families who had been in the NICU, reported that the most concerning environmental factor was lack of space at the bedside, followed by the monitor alarms and lack of privacy with their baby. Noise, lighting and privacy for meetings were a concern for much fewer families (8-20%). However, in their review of the literature, Spencer and Edwards (2001) suggest the noise levels in the NICU cannot be underestimated in their effect on impairing communication and emotional and psychological stress on parents, already emotionally stressed due to the prematurity or illness of their infant. These authors also point out that, besides noise, other sensory influences and their effects on parents in the NICU such as smell, temperature, vision and taste have not been well researched.

For some parents, the environment is not a primary source of stress, rather it is the appearance of their child (Wereszcak, Miles & Holditch-Davis, 1997). Brunnsen and Miles (1996) report in their study of 57 mothers of medically fragile infants did not find the NICU environment a highly stressful aspect of their experience. Rather, seeing their infant experience pain and difficulty breathing, while being unable to comfort their child was most stressful. Since medically fragile infants are defined as those who experience particularly long or repeated hospitalizations, these mothers may have become used to the intensive care environment, suggesting that the NICU is particularly distressing shortly after admission. Other authors also report mothers being distressed by the appearance of their babies, with both intrinsic attributes such as the size or behaviour of the baby (Bialoskurski, Cox & Hayes, 1999), and extrinsic attributes such as the tubes and wires attached to the baby (Dobbins, Bohlig and Stuphen, 1994) being stressful. Shields-Poe and Pinelli (1997) note that the most powerful variable associated with stress scores for their sample of 216 NICU mothers and fathers was how they perceived the severity of their child's illness.

The NICU is different from other pediatric settings because parents have not had time to develop relationships with their child outside the womb. First time parents are coming to terms with actually being a parent while coping with their baby's illness. Even NICU parents who have had other children, although they may feel more established in their identity as parents, are coming to terms with this different parenting, which likely includes fears for their infant's life, coupled with little contact and little control over their child's experience (Dobbins, Bohlig, Sutphen, 1994). Another difference in the NICU setting is that as mothers are beginning to cope with the health and hospitalization of their newborn, they are also always recovering from what is often a rushed, traumatic birth following a potentially lengthy period of distress in pregnancy, related to anticipation of a sick or early child, and faced with immediate separation from their newborn child. Being separated from their newborn can be significantly stressful to mothers. Ill and premature babies are often taken to the NICU immediately following delivery. Parents do not always get to see, much less hold or touch their infants due to the critical nature of the baby's condition. Even once the mother is able to attend the NICU, often the equipment, the baby's illness and nature of the treatment still precludes physical closeness, which can delay the development of parental relationships (Bialoskurski, Cox & Hayes, 1999; Nystrom & Axelsson, 2002). Parents have described feeling like strangers, observers, visitors to their own baby, where they wish they could hold, take care of and comfort their baby (Landzelius, 2003). In her ethnographic research, anthropologist Landzelius (2003) describes her observations of mothers in the NICU as "a visitor, a spectator, a satellite figure", and yet one mother related the following during an interview:

> 'the baby is the center of my being, everywhere I go, everything I do, when I'm waking, dressing, eating, whatever, it don't matter, he's with me, in my thoughts, in my heart—he is my heart, he's in here [*she taps her chest]* or he's kinda still in here *[she drops her hands to her abdomen]*' p.11.

Another parent, Peggy Stinson, only days into her extremely premature child's life, after she has been discharged from the hospital, realizes that the separation at birth continues for the child's hospitalization:

> I keep thinking about that [other] little boy crying so pitifully Saturday night, with nurses oblivious to his need, his mother unaware. If Andrew lives long enough, he will lie crying in the nursery countless times, hungry or lonely or frightened or in pain, and I will be somewhere else, working around the house or playing with Jenny or relaxing with friends, and I won't even know (brackets added, Stinson & Stinson, 1983, p.36)

Clearly, there is great dissonance in the internal feelings of mothers and the role they assume when entering the NICU. What must it be like to feel you are *visiting* your own child, your heart?

Parents and Health Care Providers

While some of the research and other literature refer to health care providers in general, the majority refer to nurses only. Meiers and Tomlinson (2003) contend that, since "(n)urses are located within the family's health experience…[they] are at least implicitly influential in the family's construction of meaning or their experience" (p.194). That is to say, nurses not only affect and are part of the experience of families, but contribute to its very nature. It is informed by this belief (extended to all health care providers in the NICU) that I proceed with the review and interpretation of this literature. Nurses are often identified as being in a logical position to support parents because of their constant presence at the bedside and their intimate involvement in the care of the infant and family (Brunssen & Miles, 1996; Griffin, Wishba & Kavanaugh, 1998). Miles, Carlson and Funk (1996) measured parents' perceptions of the helpfulness of support from various individuals during their NICU stay. While mothers and fathers both reported high levels of support from each other, NICU nurses were also perceived to be highly supportive by both mothers and fathers, suggesting that nurses have an important role in helping both parents cope with the experience of having a child in the NICU.

Researchers have identified many ways in which nurses can support mothers in the NICU. For example, reassessing their understanding and degree of worry about their child's condition; expressing sensitivity to how parents perceive periods of pain, unresponsiveness and breathing difficulties in their child; acknowledging the difficulty inherent in seeing one's child ill and the resulting restriction on enacting their parenting role; and actively seeking opportunities for the parent to participate in the infant's care are all helpful initiatives (Brunssen & Miles, 1996; Holditch-Davis & Miles, 2000; Nystrom & Axelsson, 2002). In their study, designed to identify Nurse Supportive Acts during a nursing intervention intended to facilitate mother-preterm acquaintance, Kirgis, Godfrey and McNeal (1991) found the most frequently performed supportive acts to include active listening, information exchange, validation and being a sounding board. These acts were performed in the hospital and during home visits following discharge from the NICU.

Based on their ethnonursing study of the nature of attachment in a NICU, Bialoskurski, Cox & Hayes (1999) suggest that the presence of the nurse serves to turn the attachment relationship from dyadic (mother-baby) to triadic. Because the nurses share the infant care with the mother, attachment outcomes may be difficult to predict, with the nurse sometimes actively hindering behaviour known to strengthen the attachment process, such as when they ask mothers not to touch their babies. Encouragement from nurses can also be seen as facilitating the attachment process. These authors suggest that attachment should be viewed as an individualized process. Nurses can support this process by promoting early physical contact between infant and mothers (Bialoskurski, Cox & Hayes, 1999; Shields-Poe & Pinelli, 1997). Nurses can also promote a more positive experience by asking about and listening to the birth stories of mothers and supporting increased involvement in the decisions concerning the child's care (Nystrom & Axelsson, 2002). Through their research on listening to mothers' stories about being in the NICU, Holditch-Davis and Miles (2000) support this by reporting that listening to mothers is as important as relaying information. They also emphasize the importance of staff appearing competent.

A limitation of this study may be the use of an *a priori* framework for data analysis based on the Preterm Parental Distress Model.

Cescutti-Butler and Galvin (2003) further explored parents' perceptions of NICU staff competency in their grounded theory research. They found that parents viewed staff competence not solely based on skills and tasks, but on a range of caring behaviour and related skills, "where staff showed consideration for parents and for their baby" (p. 756). Concepts key to this understanding were identified from the data and included good communication between staff and parents, parents not feeling like a burden, parents feeling in control on the unit and parents having the choice to observe tasks/procedures being performed on their baby. These caring behaviours require staff to share responsibility with families and place a greater emphasis on supporting parents, which may, in turn, lead to parents feeling less like 'guests'.

Sadly, often what parents perceive to be holding them back from fulfilling more of their parental role are nurses (Fenwick, Barclay and Schmied, 2002; Hurst, 2001; Nystrom & Axelsson, 2002). Griffin (1990) reviews the literature and discusses how nurses can be barriers to parenting in the NICU. She notes that nurses may sometimes only focus on giving care to the infants and not parental needs. This may be supported by the structure of the unit, where technical work is rewarded more than the socioemotional work of supporting parents' needs. In situations where the parents are drug abusers or 'difficult', nurses may be even less willing to provide support. Nurses may not support parents caring for their child simply because they consider the tasks in question to be within the scope of nursing. Griffin notes such behaviour as not waiting for parents to bathe their child, or taking an inconsolable baby from his mother's arms to calm him may send messages about the adequacy of their ability to care for their own child. There can also be a sense of competition between the parents and the nurses, as to who takes care of the baby "better". Early on in Emily's (born at 24-weeks gestation) hospitalization, her mother watches her nurse, Leslie, change Emily's diaper "with admiration. She handled the baby so deftly. But the procedure made me feel my distance form Emily. Even this most basic element of baby care, diaper-changing, was performed in this hermetic setting" (Mehren, 1991, p.95). Clearly, nurse behaviour can have a disempowering affect on parents in the NICU.

In their qualitative study based on interview data with 44 mothers three years after the birth of their premature child, Wereszczak, Miles and Holditch-Davis (1997) found mothers attributed a high level of stress to staff relationships. They report being surprised by this finding, because previous studies (done by Miles and colleagues, 1989; 1991; 1992, as cited in Wereszczak, Miles & Holditch-Davis, 1997) done with parents during the infant's hospitalization reported few problems associated with staff relationships. They suggest this discrepancy may be related to the ability of parents to adequately assess and rate stress related to providers while their infant is under the provider's care; they may have had a strong need to see the provider's care as adequate. Or, they might not have felt safe expressing these concerns to a researcher while their infant remained dependent on the staff for care. In their phenomenology of mothers being separated from their newborn, Nystrom and Axelsson (2002) reported that when mothers felt as if they received enough information, that staff cared and took time to talk to them, and a sense of community with other mothers and their partners, they experienced trust. However, mothers were at risk of feeling despair, powerlessness and like outsiders when the NICU staff made decisions about their babies, "who she feels is still part of herself although not actually with her" (p.280). How do parents of babies in the NICU make sense of the experience? Some authors suggest they "play the game" (Fenwick, Barclay & Schmied, 2002).

Playing the Game

In their grounded theory study, Fenwick, Barclay and Schmied (2002) described that in order to become close and gain access to their child when *visiting* them on foreign ground and on other people's terms, they realized they had to adapt to the nursery environment. This includes gaining an extensive education about the technology and people in the nursery, as well as learning what expectations were placed on them as mothers. Specifically, the mothers strategically figured out whom to ask for assistance, to always be polite in order to be "allowed" to look after their baby and to ensure their baby's best care in their absence. Kim Owens (2001), a mother whose twins were born at 26 weeks gestation (one died shortly after admission), recalls "struggling" with her feelings towards her baby's caregivers. She describes feeling very grateful to the team of primary nurses but also says "I did not dare show my frustration for fear of how she might care for my daughter when I was not present" (p.69). Hurst's (2001) ethnographic study focuses strongly on this description. She suggests a constant feature of maternal experience was struggling to safeguard their baby in the NICU. Her research also supports the metaphor of parents playing the game in NICU, describing an overriding characteristic of the mothers as "their sophisticated analyses of newborn intensive care that they used to develop a repertoire of actions to protect their babies" (p. 54).

The mothers in Fenwick and colleague's (2002) study hoped that by proving they were capable and good mothers (by the nurses' standards), they would ultimately achieve greater access to their baby. The authors suggest that by creating a positive relationship with the nurses (through playing the game), mothers gained confidence, felt comfortable and became familiar with the unit and their baby. Within a positive relationship, and as time progressed, there was less need to use these strategies. Raines' (1998) exploratory study of maternal values in the NICU supports the finding that mothers perceive nurses as having information that they need. Her participants described "a yearning to share in the special insight and knowledge nurses possessed about their infants" (p.44). Yet, in Bruns and McCollum's (2002) mixed methods survey research involving mothers, registered nurses and neonatologists, mothers described receiving conflicting information from different care providers. At the same time, nurses commented on making every attempt to reinforce information provided by physicians and other specialists.

Margo Charchuk (with Simpson, 2003), a former NICU mother and scholar, writes eloquently of the strong loyalty that NICU parents feel towards their babies. She suggests that loyalty is a way for parents to express their deep love for their babies when they are unable to do so through normal caretaking, and that health care providers can encourage this loyalty by recognizing the baby as a unique human being. When loyalty becomes more driven and goal directed, she suggests this is hope for the future of the baby. She suggests that much of parent behaviour can be understood as being consistent with the need "to protect and sustain hope for a critically ill child" (p. 41). For example, she states that if a parent's hope is to hold their child, they will find a provider who will help them, and further seek out any health care provider who will encourage their hope or support them to take actions that nurture their hope. Perhaps understanding the parents' loyalty and hope reframes the game-playing metaphor.

Relationships

Psychologist Barbara Kalmanson and psychiatrist Stephen Seligman (1992) write that family-provider relationships are the basis of all interventions. While they are referring specifically to their work with infants and toddlers determined to be at risk for mental health, socioemotional or developmental problems as a result of parent-child relationship issues, their concerns and assertions are also applicable to looking after physically ill infants in the NICU. They call for providers to "pay careful attention to their own relationships with the infants and families with whom they are working" (p.48), as the success of even the most simple intervention (e.g. prescribing antibiotics) depends on the quality of this relationship. When parents feel understood and supported by the provider, this can in turn lead to positive impacts on the parent-child relation (Kalmanson & Seligman, 1992; Van Riper, 2001). Although, again, this conclusion may seem to be more applicable to parents and infants who are in treatment for issues in their own relationship, there is an important application that may be made in order to better understand NICU parents. Eventually they take their baby home, and find they suddenly have full responsibility for a child, and that their own attachment to the child has been fundamentally challenged by the circumstances of the baby's birth and life thus far (Bialoskurski, Cox & Hayes, 1999; Nystrom & Axelsson, 2002).

Fenwick, Barclay and Schmied (2001) identify the mother-nurse relationship in the Level II NICU as both the context and method by which nursing care is delivered. Through a grounded theory study, including interviews with mothers and nurses, they report that "chatting" or "social talk" is the process through which positive interactions are "initiated, maintained and enhanced" (p.583). A process took place where as the nurses chatted the comfort level of the women increased, encouraging them to feel safe to disclose and ask questions of the nurse. As the mothers felt safe and the nurses gained insight to their world, a real two-way dialogue occurred, where both participants shared equally their life experiences. I note that in a Level III nursery, where babies are more acutely ill than Level II, chatting may not occur in the same way.

Jacqueline McGrath (2001) cites Thorne and Robinson's (1989, in McGrath, 2001) model of guarded alliance to understand relationships between parents and providers in the NICU. In this model, originally developed from research of chronic illness, families move through three stages in developing relationships with health care providers. At the beginning, families engage in *naïve trust*, assuming everyone would act in the best interest of their relative; unavoidably differences would come up and the families would become *disenchanted*. Finally, with more knowledge and experience, the families establish a *guarded alliance* with providers because they need to be involved and in control of their relative's care. Guarded alliance does not suggest the families were completely satisfied, but rather, were beginning to get their needs met by knowing when and who to ask for information. McGrath suggests that this model can be helpful to NICU staff to understand parents' needs as guided by where their experience situates them in this model.

How would parents advise NICU providers as to their needs? In a qualitative study, 102 parents (51 couples) of chronically ill children (aged 7-14) were asked, in part, what advice they would give to nurses and physicians who looked after families like theirs (Knafl, Breitmayer, Gallo & Zoeller, 1992). The most frequent advice mothers would give and second most frequent for fathers concerned the interaction style of the provider. They suggested that empathy and a genuine concern for the family was important. Other advice included providing accurate, complete information that communicated but downplayed negative aspects, establishing a relationship with the child as a person, and acknowledging and enhancing parental competence in caring for the child. These researchers may have been limited in achieving deep insight to their questions due to the relatively large sample size for qualitative research.

When families perceive relationships to care providers in a positive light, they are more likely to seek support when they need it. Van Riper (2001) reports a descriptive and correlational study that measured and compared maternal perceptions of family-provider relationships in the NICU with overall well-being in the family. Mothers who perceived their relationships with staff to be positive and family centred were more satisfied with care and reported higher levels of psychologic well-being and were more likely to seek help from care givers. This study underscores the importance of family-centred care in the NICU.

Family-Centred Care

Family-centred care is commonly considered to be an ideal philosophy for general and intensive pediatric and neonatal care (Fenwick, Barclay & Schmied, 2001, 2002; Hurst, 2001; Sydnor-Greenberg, Dokken & Ahmann, 2000; Tomlinson, Thomlinson, Peden-McAlpine & Kirschbaum, 2002; Van Riper, 2001). Tomlinson and her colleagues (2002) emphasize the importance of the nurse-family interface and the nurse's sensitivity to the emotional, role and practical demands of the family in crises in family-centred care. Other authors have referred to family-centred care as ideally a partnership between parents and providers, each recognizing and embracing the expertise of the other (Bruns & McCollum, 2002). Yet, often the structure and methods for enacting this type of care are not well established (Bruns & McCollum, 2002; Hurst, 2001; Lawlor & Mattingly, 1997; Tomlinson, Thomlinson, Peden-McAlpine & Kirschbaum, 2002).

Occupational therapists Lawlor and Mattingly (1997) ask several questions related to how families can be made more central in pediatric care. They ask what such collaboration with family should look like and be negotiated. How will including the family members affect the role of the practitioner and the way that interdisciplinary teams work together? What if family members do not seem to want more involvement? They suggest the common presumption that family-centred care is simply added to traditional health care models is unrealistic. Rather, they contend it requires a redefinition of practice and will only be realized "when the radical nature of the required social shift in human services is recognized" (p.265). They recommend research is needed that examines relationships between providers and parents, the meanings of illness in the context of family life, characteristics of family-centred care and the influences of organizational structures and professional cultures on service delivery.

Hurst (2001) concurs, in her ethnographic study, that the structure of NICU health care impacts implementation of family-centred care. She reports that mothers were acutely aware of the demands on nurses, such as lack of staff that lead to an inadequate amount of time to provide "safe, competent continuity of care" (p.55). Linked to this, lack of knowledge on the part of providers was another barrier to family-centred care. Partly because of the structural constraints, nurses were unable to have adequate resources to provide their best care. Hurst notes that the mothers sought to negotiate relationships with nurses and actively participate in their baby's care, however these actions were sometimes unrecognized or misconstrued by health care providers. This is turn affected how the mothers reacted to providers in future interactions.

Morality in the NICU

As already suggested, the nature of caring for life in its most fragile form, premature and ill infants, presents many ethical dilemmas (Pinch, 1990). The common dilemmas, including considering the discontinuation of treatment, resuscitation of extremely premature infants, will not be reviewed here. This review of the literature, and indeed, this proposed study, seeks to reframe the ethical issues in NICU to include an attention to the moral character of daily care, as situated in the relationships between parents and health care providers in the NICU. Raines (1996) reminds us that no matter the outcome of the NICU experience, upon discharge, the infants depend on their parents for their survival and well-being. She suggests that in order to provide morally right treatment in the NICU, parents' values and experience must be taken into account, and that, historically, this has not been the case. Instead, underlying the expansion and development of neonatal care has been the assumption that "if the health care system delivers to the parents an infant in some semblance of good health, those parents will carry on with the gratitude for a job well done by the nursery staff" (p. 8). Robert and Peggy Stinson (1983) are parents who have expressed in print their belief that the 'care' provided to their premature son only prolonged his suffering and death, and was done so in a manner that disregarded the feelings, beliefs and needs of their family.

However, the qualitative research of Pinch and Spielman (Pinch, 1990; Pinch & Spielman, 1990; Ellenchild Pinch & Spielman, 1996) found that families do not necessarily articulate a struggle with or even awareness of moral decisions in the care of their baby. In Pinch's (1990) phenomenological study, the parents expressed no feelings of ownership of responsibility for decision making. Rather, parents accepted the professionals' role as decision makers. They were the passengers of the journey, not the engineers (Pinch, 1990, p.16). Pinch and Spielman (1990) identify the concept of *medicalized parenting*, to describe the passive role the parents in their study described toward ethical decision making, and note that for most parents, this was an acceptable situation, in light of the stress, the complicated nature of the technology, or the desire to capitulate to the provider's expertise that they were experiencing. These authors go on to report that most of their participants described feeling disconnected from their child, along with feelings of emptiness and depression at their situation. This seems different from results of studies previously mentioned in this review. For example, although parents did often perceive themselves as visitors, it seemed at the same time they felt connected to their baby and would not have accepted a passive role towards involvement with their baby's care. In their follow up study with these parents at four years post discharge, Ellenchild Pinch and Spielman (1996) report that the parents continue to emphasize stress, emotions and disconnectedness to their infant as they recount their stories of having an infant in the NICU. Perhaps it follows from this that the families described integrating the child into the family as difficult. General concerns about money and the future of the family were expressed, and parents did suggest that their informational needs were not met during the NICU experience, including knowledge of their baby, skills for coping and guides for behaviour in the NICU.

In their discussion and review of the literature Becker and Grunwald (2000) suggest that the weight given to the parental role in decision making varies among providers. These authors examine the contextual nature of ethical decision making in the NICU and suggest that this includes the social structure of the unit, the hierarchy of staff, including both power differentials between groups and interest differentials within groups (e.g. residents interested in learning experiences compared with nurses interested in caring for responsive infants, potentially influencing them toward less aggressive treatment) as well as the manner in which professionals approach moral decision making. At times, there are legitimate time constraints in the NICU when professionals are obligated to make moral decisions. Other times, Becker and Grunwald emphasize the importance of communicating with parents in regards to ethical decision making, including attention to bias in the presentation of information. They conclude by suggesting a move to a more collaborative model of care within the NICU, as well as an acceptance of interaction data, which gives some weight to the relational potential of the baby (Dormire, 1989, as cited in Becker & Grunwald, 2000).

In their discussion of the moral authority of parents in the NICU, Zaner and Bliton, (1991) highlight the many uncertainties inherent to moral decisions in the NICU. Uncertainty in the sense of not knowing where individual infants fall on the frequency distribution of survival, and the possibility of making an error in judging where particular babies are located on this curve. As well, uncertainty on the part of parents who do not know who to ask, what to do, or who is able to do whatever it is that should be done. These authors eloquently outline the complexities involved in making ethical decisions in the NICU, taking into account the (American) legal expectations of the court, the medical expectations that physicians are more than information providers and the societal expectations that parents are responsible for and to their children. Most basically, this expectation of parents "involves promoting and safeguarding the newborn's moral status as a person, to enable the infant to become a full moral agent within the surrounding moral community" (p.21). Zaner and Bliton take note of two assumptions imbedded in this responsibility. Parents must have moral authority to make decisions on behalf of their child, and other persons may make some (routine) decisions for the child, their primary responsibility is to fully inform parents and support them in decision making. In light of Pinch and Speilman's (1990; Ellenchild Pinch & Speilman, 1996) research discussed above, where some parents do not even realize moral decisions have been made, this seems a very difficult proposition.

A Different View

This literature review has revealed that many researchers and authors have attended to the situation of parents in the NICU. It serves to increase my understanding of issues already identified. It may lead the reader to ask, what will be different about this study? Is another qualitative study on the experience of NICU parents necessary? In other words, we have come to the "so what?" question that should be asked before any research project. My own curiosity that was sparked and developed during my neonatal nursing practice coincides with a gap in the literature—I seek to understand parents' experience through a different framework—a moral framework that situates ethical action in relationship. Congruent with the conceptual goals of this research what follows is a short summary of relational ethics that is structured primarily from the research of Bergum and Dossetor (2005).

Relational Ethics

Although I am presenting it as somewhat "new", relational ethics is an approach to health ethics that has perhaps always existed, since the importance of relations is simply lived in day to day life. Historical figures such as Jesus

Christ and Mahatma Ghandi can be considered great relational practitioners. Relational ethics has been written about before, by R. Melvin Keiser (1996), who develops the moral philosophy of H. Richard Niebuhr in *The Roots of Relational Ethics*, and the term relational has been used by nurses and others discussing relational narrative (Gadow, 1999), relational pedagogy (Bergum, 2003), relational ethic of care (Parker, 1990), relational autonomy (MacDonald, 2002), relational ethics (Austin, Bergum & Dossetor, 2003; Bergum, 2004; Davidson, 1977; Gadow, 1995; Whatmore, 1997), relational moral (Estola, 2003) and a relational approach to care (Greenwood, Loewenthal and Rose, 2001).

The core elements, or themes, of relational ethics as identified by Bergum (2004) and her colleagues include environment, engagement, embodiment and mutual respect. Although they are presented somewhat separately in this text, in real life we experience the core elements as entwined and interrelated; they supplement each other and they are difficult to distinguish. Further, Bergum suggests these themes are not final, that is to say that they are not all there is to relational ethics, and it would be incomplete to reduce relational ethics to these themes alone. Perhaps because relational ethics is so grounded in context and human experience, "the themes only come alive in the disorderly realities of practice rather [than] in orderly requirements of theory" (p.488).

Environment

One way to think about relational ethics is simply as a reawakening, an admission of the way things are, the way we experience the world. This requires keen attention to the environment around us. We move from considering in a general way what is a right and wrong way to act to ask: what is happening here, now? How are we defining this problem, who is defining this problem? Who is this person, who depends on him, who knows him? What might we do? How should we choose what to do, who should choose? It is being in the particular moment when and where ethical action is demanded. Bergum (2004) suggests that within this approach, we can understand that environment is not something that is only external to us. It offers a space where we can bring different types of knowledge to the specific situation to ask questions and consider ethical complexities. Attention to the environment, remembering that we are in the environment and we are the environment, is important; it reveals the fallacy that objective rules can help to promote—that life is simple or can be simplified (Bergum, 2004). Relational ethics does not *make* situations complex, but has room for the complexity that exists in the environments of our daily lives, compounded by illness, birth, death, recovery or any combination of these.

Engagement

Moving toward the other, in an attempt to understand experience, is a movement toward engagement. Engaging with another person involves approaching another in an open and receptive way with an acknowledgement of the humanness of both people. In a relational approach "ethical professional practice requires the personal, the intersubjective" (Austin, Bergum & Dossetor, 2003, p. 49). Bergum (2004) suggests that, if we understand relationships to be ethical, a lack of involvement, or disengagement must be recognized as an ethical issue, in the same way we recognize over-involvement between health care providers and patients or families as such.

How engagement happens is unpredictable and context-dependent. Elizabeth Mehren's (1991) memoir describes her experience of having a child live and die in an NICU. Near the beginning of the hospitalization, Mehren is just coming to know her daughter's primary nurse, Leslie. They have established a solid beginning to their relationship. One day, Mehren learns that Emily has had her first episode of bradycardia, or slowing heart rate. Although increasing frequency of bradycardia's can indicate underlying illness, infrequent episodes are normal in the course of a premature baby. What seems shocking was Mehren's reaction when Leslie relates what she said to Emily after the episode: "'I shook her, called her a little shit, and told her that if she ever did that to me again, I'd smack her,' Leslie said". I expected to read on that Mehren requested Leslie never care for Emily again, but instead: "I leaned over Emily's isolette and put my mouth next to the porthole. 'You hear that, Emily?' I said. 'She means it. You listen to Auntie Leslie'" (p.98). This mother totally embraced the nurse's co-ownership of the baby. By suggesting that the dip in Emily's heart rate did something to her, the nurse was saying she was affected by this baby's progress, and that she had a stake in the child's life. From then on, with the commitment clear between the two women, their relationship develops into a supportive one, with them coming to know and trust each other, as they both struggle to take care of the baby. However, this same situation may have had devastating effects on a different parent.

Embodiment

While many professionals in health care are quite comfortable with detailed scientific, objectified knowledge, it seems much more difficult to embrace the knowledge of our bodies, our guts, our heart, and our muscles. When an NICU nurse approaches a bedside where an infant is tightly restrained to his bed and her first reaction is a bodily one, one of horror and injustice, evidenced by feelings of worry and anxiety, she is right to trust these feelings and allow them to bring her more fully into the relational space between her and her patient (Austin, Bergum & Dossetor, 2003). It is reasonable to think that after considering the situation the manner of restraint may be justified for the safety of the baby, or required for a procedure. However, the embodied reaction is valuable as it provides a means to prevent unnecessary restraint, overly harsh restraints, or may even be the impetus to suggest a short break from the restraints. It would be taking the restraints for granted, or not noticing them, or noticing them without a question that must be recognized as an ethical issue. "Embodiment calls for healing the split between mind and body" (Bergum, 2004, p.492), it calls us to relate to those in our care and acknowledge our own "vulnerability as [we] resonate with the other's pain" (p.494). Bergum recognizes it is a "fine balance" to embody the experience of the other, while remaining fully aware we are also distinct (p.494).

Mutual Respect

In the middle of this complexity, is perhaps a simple idea, but one that seems to me inextricably part of striving for relation: kindness. It should not be downplayed that relational ethics involves being kind to people, and one has to ask how much more moral the world would be with more kindness. However, relational ethics cannot be reduced to simply "being nice". Just the opposite; being true to other people in our lives, including patients and others depending on us, demands that we challenge those ideas or actions that we are worried about. It does not allow us to simply categorize the uninformed or immoral choices of others with whom we are involved as "none of my concern" or "their right". Rather, without dominating, stigmatizing or abandoning, we embrace the opportunity to question each other, with full knowledge that our support of the *person* is unqualified. In order to truly respect each other, "there is a need to learn ways to engage the other, the *you*, without reducing *you* to the same as *me*, or *me* to the same as *you*" (Bergum, 2004, p.495). Respect for others who are different from us or have different views and expectations from us is not easy.

Research Question

What makes this research unique from the studies listed here is an attempt to understand the experience of parents not only from a clinical perspective, but from a moral perspective, one that acknowledges the obvious as well as the more subtle and finely nuanced ethical obligations and complexities inherent to their experience, particularly in the interactions between NICU parents and their care providers. The research question in this proposed study is: *How do NICU parents describe their relationships with health care providers?*

CHAPTER THREE

Methodology and Method

Methodology

Anyone who wants to know the human psyche will learn next to nothing from experimental psychology. He would be better advised to abandon exact science, put away his scholar's gown, bid farewell to his study, and wander with a human heart throughout the world. There in the horrors of prisons, lunatic asylums and hospitals, in drab suburban pubs, in brothels and gambling-hells, in the salons of the elegant, the Stock Exchanges, socialist meetings, churches, revivalist gatherings and ecstatic sects, through love and hate, through the experience of passion in every form in his own body, he would reap richer stores of knowledge than text-books a foot thick could give him, and he will know how to doctor the sick with a real knowledge of the human soul. -- Carl Jung

The purpose of this study was to better understand the relationships between NICU parents and care providers as a space where moral action occurs. In order to move toward this understanding, I have explored these relationships in a deep way, from the parent's perspective, aiming to gain insight which may inform health care practitioners who work with these parents and their children. Qualitative research offers a way to this understanding, because it is grounded in recognizing and exploring the meaning and complexity of human experience, particularly the experiences of health and illness, as a way of coming to better understand the experience. An interpreted description of the experience can reveal insights that are relevant for clinical practice in the NICU. Qualitative research is "an activity of reflection and practice, whose intent is to give rise to a wiser and more meaningful portrayal of social phenomena" (Rothe, 2000, p.21).

Philosophical Grounding for this Study

The philosophical grounding for this study is incorporated within a worldview that recognizes that not everything can be understood by measuring, and that, in fact, not everything can be measured. Underlying this research is the philosophical assumption that there is not one objective truth or one all-knowing objective position from which the world can be seen in its entirety. Since human experience is complex and contextual, it is impossible to describe any phenomenon fully and exclusively, and therefore there could be many true, yet different accounts of the same phenomenon. Each account is at least in part dependent on the viewpoint of the observer, the researcher, the recorder. The research then becomes a project of inter-subjectivity between participants and researcher. My intent here is to make a contribution to the scholarly discussion of moral practice in health care, as well as to influence the practice of individual care providers. Using nurse philosopher Sally Gadow's (1999) metaphor of a coral reef, I understand relational ethics as an emergent way of looking at ethics, which comes from and dwells beside modern, reason-based approaches, just as reason-based approaches are supported by and emerge from traditional, pre-reflective conceptions of ethics. She reminds us that in the complex, integrated biological environment of coral reefs in the ocean, the life of each organism is integrally related to all of the others, and uses this image as a way to understand the interdependent nature of approaches to ethics:

> The flourishing of premodern, modern, and postmodern ethics in nursing can be imagined metaphorically as the biodiversity of a coral reef where different life forms integrate and where organisms even after their death provide a structure that supports life. At the level of immediacy, we are immersed in ethical currents that carry us safely through situations where reflection would be impossible. When crosscurrents require us to reflect and to hold a position, an edifice of ethical principles offers a structure for steadying ourselves. Finally, there are situations where no edifice can alleviate our vulnerability, and in those cases we can only turn to each other and together compose a fragile new form of the good. (p. 66).

The relationships between parents and practitioners in the NICU are more than just means to an end, even the worthy ends of health and healing. These relationships between health care provider and person in care are instead, ends in themselves (Schroeder, 2003).

Method

This project uses an interpretive descriptive method as described by Thorne, Reimer Kirkham and MacDonald-Emes (1997; see also Thorne, Reimer Kirkham & O'Flynn-Magee, 2004). These authors suggest that interpretive description be regarded as a "generic" nursing approach to qualitative research and is appropriate for "the smaller scale qualitative investigation of a clinical phenomenon of interest to the discipline" and is capable of "informing clinical understanding" (Thorne, Reimer Kirkham & O'Flynn-Magee, 2004, p.5). This method serves to guide the creation of an "interpretive account that is generated on the basis of informed questioning, using techniques of reflective, critical examination, and which will ultimately guide and inform disciplinary thought in some manner" (Thorne, Reimer Kirkham & O'Flynn-Magee, 2004, p.6). The following text was generated from those who have lived the experience, parents of babies admitted to the NICU, from their responses to open-ended questions and in conversation. The outcome is a detailed, nuanced interpreted description of NICU parent-provider relationships, illustrated by specific examples. The product of an interpretive description is a coherent, conceptual description that includes and accounts for both commonalities and individual differences that characterize the phenomenon under study. Ideally, the products of interpretive description have clinical application potential and make sense to experienced practitioners (Thorne, Reimer Kirkham & O'Flynn-Magee, 2004). The use of this and other generic qualitative approaches has generated a discussion in the nursing literature. Caelli, Ray and Mill (2003), encouraging a critical debate to ensure these methods are done well, suggest researchers must make explicit their own theoretical position, attend to congruency between methodology and methods, outline strategies to establish rigor and identify the analytic lens used to examine data.

The Researcher

As fitting for qualitative inquiry and relational ethics, it is important that I situate myself, lay bare some of my own biases and blind spots (acknowledging that to do this completely is impossible) and explain why and how I came to ask this research question. I come to this inquiry as a registered nurse who has spent most of my practice directly caring for infants and their families in the Neonatal Intensive Care Unit. My practical experience also includes coordinating the process of human organ donation, from offering families the opportunity to consider donation right through to surgical recovery and placement of the organs; and providing acute bereavement support to families whose relative is dying from a sudden, acute brain injury. My interest in ethics became formed while witnessing the suffering of others and by being privileged to share in the intimate experiences (birth, death, illness, grief) of the lives of strangers who, for a few moments, were no longer strangers. And, although I was involved in and struggled through several instances of ethical dilemmas, end-of-life care, human organ distribution, and conflicts with families around treatment decisions, it was not only here that my attention lingered. I am deeply concerned with the ongoing, inherent moral character of the practice of health care professions. From this perspective, it is important to consider not only what we do with patients and families, i.e. what decisions we make, what types of treatment, what types of caring interventions, but how we do all of these things. It also seems important to understand and focus on the importance of our interactions with the others in our lives and practice.

Moved by wanting to practice nursing in a morally attentive and responsive way, I asked this question and conducted this research. The notion of nursing as a practice is important for understanding my focus on relationships, because a practice itself is a commitment—several actually, to ourselves, our patients and our colleagues. Unlike science which has traditionally been the neutral quest for answers to empirical questions, or art as the search for or creation of beauty, *practice* seems to mean being there every day, a promise. Bishop and Scudder (1997), nurse and philosopher, argue that nursing is not adequately explained as an art or a science, but is better articulated as a practice. This, they contend, is because "(i)n a practice the goods or values of a people become concretely instantiated in the world in which they live. The ways of being, doing, and the ends sought are integrally related to each other…" (p.83).

Thus, the moral nature inherent in nursing is captured in nursing as practice, as this notion makes relevant not just what we mean to accomplish, but how we achieve these ends and who we are while we seek these ends. Scientific knowledge was integral to my intensive care nursing experience, and I found great joy caring for people in an artful manner. However, it was in the thick of practicing nursing that I realized the moral demand, in those moments of eye contact between myself and distraught parents desperately wondering if they could trust me, not only my knowledge of complex heart malformations, or even whether or not my touch was soothing and healing to their child, but could they trust me to remember that they and their child were more than another difficult family or interesting case?

Yet, this is not all. Perhaps what I most need to make explicit is an even more personal influence. Since I was a nurse in the NICU, I have become a mother. During my child's newborn days and nights as I, like most new parents, lived through the intense emotional and practical changes to my life, I found my thoughts drawn sharply back to parents in the NICU. Intensified by the love and fatigue I was experiencing with my healthy, term baby, I visualized the faces of parents I had known and understood them differently. I wondered—had I done enough? Did I live up to, not only the clinical commitment, but the moral commitment made to them implicitly as they walked in the door to the NICU? These memories and reflections, combined with my clinical intuition regarding the moral obligations in our relations with families, have lead to my interest in better understanding the moral nature of the relationships between NICU parents and health care providers.

Research Design

Setting.

The Northern Alberta Neonatal Intensive Care Program in Edmonton, Alberta, operates 65 neonatal intensive care beds on two sites, 51 at the Royal Alexandra Hospital and 14 at the Stollery Children's Hospital, within the University of Alberta Hospital. The Stollery site is relatively unique in scope, as it is primarily a surgical site for infants, with babies being transferred in for surgery and out again. Since the program is regional in scope, it is common for babies and parents to be transferred throughout the system as the baby's condition changes. Three of the babies in this study were cared for at both units. Participants for the study must have had experience at least one of these intensive care units.

Participants.

In order to answer a question in a qualitative way, that is, to achieve a deep, rich understanding of a phenomenon, there must be enough data to provide a rich description. Sandelowski (1995) suggests a good principle to follow regarding the number of participants in a qualitative research study:

> An adequate sample size in qualitative research is one that permits—by virtue of not being too large—the deep, case-oriented analysis that is a hallmark of all qualitative inquiry, and that results in—by virtue of not being too small—a new and richly textured understanding of experience.

The number of participants in a qualitative study cannot be such that it prohibits the deep, rich level of description and interpretation. Too many participants can actually diminish the value of the study (Morse, 2000). Determining the number of participants depends on many factors, such as quality and amount of data, scope of the study, nature of the topic, indirect data, and the specific qualitative method and design used (Morse, 2000). The parents I met for this study spoke readily of their relationships with NICU practitioners, as I had anticipated based on first hand accounts from parents (Mehren, 1991; Powell & Wilson, 2000; Stinson & Stinson, 1983; Woodwell, 2001) and my clinical experience. Morse, (1991) refers to "the myth of saturation" (p.141) in qualitative sampling. Saturation is said to be reached when no new information is being obtained from participants. Morse contends that "in reality there are a myriad of experiences that may or may not be pertinent or significant" and that it is the researcher that decides the significance of new (and by extension, of already gathered) information.

Parents whose baby had been admitted to a Level III NICU (either the Stollery or Royal Alexandra site) were invited to participate in my study when close to discharge by an advanced practice nurse (APN) who had access to all families in one of the hospitals. Although three families had experience at both hospitals, none were recruited directly from one of the sites, related to the nurse practitioners' busy schedules. The APN provided them with an information sheet about the study and asked them if they are interested in learning more about the study (See Appendix A). When parents were interested, their contact information was forwarded to me and I contacted them by telephone. We then discussed the details of the study and, if they were interested in participating, an interview was scheduled. At the time of the interview the consent form was completed. My contact information was on the information letter, freeing parents to contact me if they needed to or if they changed their minds about participation. All interviews were planned to take place after discharge, in order to prevent any possible influence from the research on the experience in the NICU. Inclusion criteria required all participants spoke English, were over 18 years of age and were available to be interviewed either in person or over the phone.

The Parents.

A total of eight parents participated in this study, including two couples. Both mothers and fathers were invited to participate in the study. The two couples who participated chose to be interviewed together; the other participants were mothers. Throughout this research text, the parents, babies and nurses are referred to by pseudonyms that I chose for them. (Although all participants were provided the opportunity to choose their own pseudonyms, none did.) Infant genders and diagnoses may have been changed to avoid identification. The families are: Christine Hayes and her twin babies Lily and Seth, Shannon Wright and her baby Beth, Jamie and John McDonald and their baby Ali, Maja and Ivan Delich and their baby Nicholas, Kate Myers and Julia, and Evan Carter and Aaron. Four babies were the first born child, Lily and Seth were Christine's third and fourth babies; Ali was Jamie and John's second child. All except one baby were born at 24-26 weeks gestation. Beth Wright was born at term with a congenital malformation that required surgery. Beth was admitted at both sites, for a total hospital site of less than three weeks. The other babies, all born prematurely, had lengths of stays that varied from two and a half months to five and a half months. Two of the premature babies had experience at both sites. At the time of the interviews, all babies were doing well, as reported by their parents. One baby was on home oxygen. The interviews took place less than one month to five months following discharge. Three families lived in Edmonton or the immediate proximity. The other three lived in rural Alberta. Demographic data was not collected and this description is offered to better understand the accounts provided by the parents and should not be considered to be representative of NICU parents in general.

Interviews.

I spoke with parents during open-ended interviews that more closely resembled conversations. All interviews were face-to-face except Christine Hayes whom I interviewed over the telephone[2]. Concrete, specific descriptions of relationships with staff were elicited. Questions I used to initiate or stimulate dialogue such as, "What was it like to have a baby in the NICU? What were your relationships with NICU care providers like? Can you describe moments where staff made a difference to you, either in a positive or negative way? What do you wish had been different about your relationships with staff? (Appendix B). I interviewed the four mothers individually and two couples together, each parent or couple once. While planning this study, I anticipated that there may be more than one interview required. However, the interviews lasted between one and two hours and all seemed 'finished' at the end of our time together. They ended when the parents came to 'the end'. All parents were encouraged to contact me if they remembered something that they wanted to tell me; none did. The conversations were audio-taped and transcribed, mostly by myself with help from two transcriptionists.

During the last five interviews, I was pregnant with my second child. At the second interview she showed her presence in my nausea and by the last interview, I was full with her, and gave birth just two weeks after. During the interviews, including the early ones where the parents did not know I was pregnant, the baby inside of me kept me mindful of the babies that were central to the stories of the parents. As we spoke of parents and staff, I was reminded that always, the baby remains the reason and the inspiration for relationships in the NICU. Sally Thorne reminds us that interview data can never be taken literally: it is a moment out of a life, not a whole life and it is a perception, an interpretation (personal communication in workshop, Jan 29, 2004).

Thematic analysis.

"The intellectual task of the analyst…is to engage in a dialectic between theory and the data, avoiding theoretical imposition on one hand, and atheoretical description on the other, in the quest for a coherent rich interpretation" (Thorne, Reimer Kirkham & O'Flynn-Magee, 2004, p.11). The analytic process began during the interviews, as I began to understand each participant's experience of relationship in the NICU, and my thoughts and reflections about the meanings and implications of each account started to take shape. Acknowledging "that the researcher and research cannot be meaningfully separated" (Hand, 2003, p.15), a reflective journal was used to develop and document interpretive ideas, processes and decisions. In relation to research, reflexivity of the researcher involves "the realization that researchers are part of the social world they study" (Porter, 1993, p.141). Being a reflexive researcher means that instead of trying to eliminate the effects of the researcher (or believing this is possible), the researcher attempts to realize and understand the effects that the researcher has on the research. This requires honest, rigorous examination of the values and influences that may affect the research (Porter, 1993). For example, as I was asking "what is happening here?" of the data, I was also asking it of myself, in an attempt to better understand and make explicit my interpretive decisions.

More structured analysis began after data collection. Overall, the questions guiding the analysis were "what is happening here?" and "what am I

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[2] I did meet Christine the day following her interview to sign the consent form when she returned to the city to attend an appointment for one of her babies. She did not have enough free time in

learning about this?" (Thorne et al., 1997, p.174). I began by listening to the taped interviews and reading individual transcripts, paying great attention to coming to know the individual accounts intimately and in context (Thorne, Reimer Kirkham & MacDonald-Emes, 1997). Then, I turned again to the individual transcripts, less with an attention to that particular narrative, but to identify phrases, sentences, and paragraphs that directly relate to the experience of relationship in the NICU. As I reread, compared and reflected upon the accounts from the parents themselves, as well as the significant statements from individual accounts, it became clear that there were many similarities, variations, connections and relationships between the stories told by these parents of their time in the NICU. I organized these phrases into initial "repositories", cutting and pasting between computer documents. Exemplars of specific themes were chosen from the data, and where outlying data did not fit, or contrasted with the identified themes. As well, sometimes participants presented situations unrelated to relations with care providers. These descriptions were included as evidence of the complexity of the experience of being a parent in the NICU. The knowledge produced was applied back to individual cases, and the questions asked, does this make sense, does this fit? A portion of the analysis occurred in the actual writing down of the themes and meanings as they were discovered and interpreted (Morse, 1994). Reflections on my practice as a neonatal nurse as well as on the interviews and the experiences of the parents themselves are used to augment and elucidate thematic descriptions.

The theoretical framework organizing the conceptualization of this study is relational ethics as originally researched and described by Bergum and Dossetor (2005) and their colleagues (Austin, Bergum & Dossetor, 2003; Bergum, 2004). This approach to health ethics recognizes and makes explicit relationships as the place of ethical action. Relational ethics is particularly applicable to this study of relationships of NICU and my interest in the "moment-by-moment" ethical nature of providing health care. This theory was used as a conceptual guide, with care to avoid using it as an impositional force

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the city for the interview. Verbal, taped consent was received prior to the telephone interview.

on the data, by coercing the words of participants to conform to preconceived expectations. The original repositories were created from the words of the parents. After much of the thematic writing was completed, relational ethics was considered (I acknowledge that relational ethics contributes much to my worldview and that even without realizing, aspects of the theory contribute to my interpretation.) I regarded relational ethics as a place for me to stand, a base or point-of-view that provided me the foundation which made it possible to open my mind to the possibilities presented by the participants. The analysis and interpretation have lead to the outcome of this qualitative research: a written account thickly describing, from the parents' points of view, the relationships between parents and staff in the NICU.

Considering the Quality of this Research

Before this discussion of quality in qualitative research occurs, I acknowledge that there has been much dialogue and debate concerning rigor in qualitative research, the whole of which is beyond the scope of this discussion. The debate concerns both practical methods of assuring the quality of research and the philosophical underpinnings of such endeavors (Emden & Sandelowski, 1998, 1999). That is, what is good qualitative research and how do we know? There seems to be no agreed upon terms or criteria to assess the 'goodness' of qualitative research. Indeed there is controversy as to whether or not it is even reasonable to consider as a possibility any guidelines that could be relevant to the many different humanistic methods, all considered qualitative (Emden & Sandelowski, 1999).

Acknowledgement (and embrace) of the complexity of human condition is inherent in the methodology of qualitative research. Therefore, attempts to understand any human experience through spoken words and to express it through written words must, by nature, allow for uncertainty. Emden and Sandelowski (1999) suggest that a "criterion of uncertainty" should be included as an "open acknowledgement that claims about our research outcomes are at best tentative and that there may indeed be no way of showing otherwise" (p.5). Recognizing this uncertainty is not an apology for qualitative methods but rather an understanding that this type of research brings with it the full and complicated richness of human experience. In this context, uncertainty is not regarded as a shortcoming or limitation, but rather as the possibility of recognizing both the impracticalities of the expectation for one attainable truth and appreciating the "richness and value of local contexts and meanings" (suggested by Richardson, 1988, as cited in Emden & Sandelowski, 1999).

Davies and Dodd (2002), writing about rethinking the concept of *rigor* for qualitative research, emphasize that rigorous research must be fundamentally ethical, where understanding ethics involves trustfulness, honesty, openness, respectfulness, carefulness, and constant attentiveness. Ethics is regarded as intertwined with the practice of research throughout the entire process. I have attempted, as one way of assuring the quality of this project, to make clear, as much as possible, my own preconceptions, assumptions and current state of understanding. I understand this process not as setting these attributes aside, but instead as the acknowledgement of my role in and influence on the research by making it explicit (Hand, 2003). It includes attention to "a sense of responsibility, accountability, partiality, and subjectivity within the research" (Davies & Dodd, 2002, p.285). I have sought to acheive this by carefully attending to the research process, through reflective and reflexive practices and by making evident the research process, even when it seemed disordered and chaotic (Davies & Dodd, 2002). Similarly, Thorne and colleagues (2004) suggest that the credibility of findings is always closely related to integrity to the interpretive process. They suggest that a good interpretive description should pass the "thoughtful clinician test " meaning that those "who have expert knowledge of the phenomenon in a particular way find that the claims are plausible and confirmatory of 'clinical hunches' at the same time as they illuminate new relationships and understandings" (p.17). The value of this research will be demonstrated then, by reactions such as these and if it contributes to an improved understanding of the relationships between parents and health care providers in the neonatal intensive care unit.

Assumptions

Some assumptions fundamental to this research project include:

1. Relationships between health providers and parents of infants in the NICU influence the meaning of the parent's NICU experience.
2. There is a moral character to the practice of health care providers
3. Ethical practice is grounded in relationship; relationship is the place of moral action.

Ethical Considerations

At root, in any research involving human beings, disregarding scope or method, there is an overall ethical commitment to doing good and meaningful research that will produce knowledge. That is, any research that is performed, no matter how low risk, must be done well in order to respect the participation of those involved. Rothe (2000) recommends reflection and knowledge of general ethical principles as important tools to achieve an ethical process and outcome in qualitative research. He suggests as a guide to reflection asking questions such as "do [participants] trust me?", "am I verifying my observations?", and "do I stand behind my findings?" (p. 170). By reflecting in this way, the researcher is able to determine motivations and perspectives that may be influencing the integrity of the study. Appropriate ethical clearance to conduct this study was obtained from the Health Research Ethics Board (Health Research Panel) at the University of Alberta. The interview tapes and transcriptions have been labelled by identification number only and are kept securely in a locked filing cabinet separate from one master list with names and numbers for seven years. Names and other clearly identifying features will be changed in all reports of the findings.

Risks and Benefits

Perhaps one of the most confounding factors when considering the ethics of qualitative research is the difficulty in predicting what will happen during the course of the research. The more unstructured the approach to collect data; the more this becomes true. It is difficult to estimate the extent of certain risks; some may be very low. However, just because certain harms can be foreseen as a possibility, they must be taken into account and prepared for. The risks in qualitative research tend to involve psychological and emotional harm. I used unstructured interviews, where I asked parents open-ended questions about what the experience of having a child in the NICU was like. In general, the participant guided the content of the interview. When necessary, I probed for further information about the relationships or lack thereof with the health practitioners. Being able to describe and understand all the details is important, since the knowledge in a qualitative study is developed from in-depth, contextual description and understanding. However, this may also be the most risky portion of the interview for the parents.

Although I have suggested that the participant remains in control of the direction and depth of the interview, this may only be true to a point. It may happen that a participant reveals more than he or she means to, as the intimate nature of the interview setting is intended to encourage the participant to open up. The participant may only come to realize this much later, in afterthought. Hadjistavropoulos and Smythe (2001) suggest these "negative psychological implications" (p. 166) can become more complicated if a negative mood state pre-exists in the participant. The complexities only increase if the disorder is undiagnosed or unknown to both the participant and the researcher. They suggest that participants should be screened for specific vulnerabilities by the researcher, and that this should be undertaken in order to prevent harm and not to discriminate against potential participants. This does not mean that those who screen as high risk should be excluded from the study, but that extra support is put in place, and extra caution be taken during their interview. These parents were all coping with the recent discharge of their premature or previously ill baby home, with perhaps the extra worries that this entails. This in itself may have predisposed them to the negative mood state referred to by Hadjistavropoulos & Smythe (2001). Even if the baby was presently completely healthy, remembering and discussing their time spent in the NICU may be very difficult, considering the NICU experience is, by nature, difficult and distressing. Although I recognized that there was potential for psychological harm to the parents, the risk of this harm was difficult to predict, and was dependent on the unique situation, including the very moment the interview took place. Each of these parents volunteered to participate in this study and expressed appreciation for the opportunity to talk to an interested stranger about this stressful time. Van den Hoonaard (2001) argues this may certainly be the case and that the risks and harms of unstructured interviews may be exaggerated by research ethics boards who may continue to assess qualitative research based on the paradigms of quantitative traditions.

I had prepared three possible strategies to address the risks of potential harm caused by the psychological and emotional stress of the interview. First, the information letter and the consent form included a statement acknowledging the possibility that the discussion may "shift toward topics I find upsetting" (suggested by Hadjistavropoulos & Smythe, 2001, p.172). Although it did not seem possible to fully inform the participant of the risks involved due to the unstructured and therefore unpredicted course of the interview, a statement such as this can alert the participant to be able to assess the potential of such harm for themselves. Second, I, as researcher, prepared personally for dealing with emotionally distressing situations that may come up. In this case, several years of experience nursing parents of neonates in varied stages of crisis, and caring for grieving families considering organ donation has afforded me practised skills in dealing with very upset people. Kavanaugh and Ayres (1998) discuss ways of recognizing and encouraging respondent-initiated coping strategies that may be helpful in dealing with upsetting situations that arise during the interview. I planned that if, during the interview, the participant showed signs of distress, a break or postponement of the interview would be suggested. Most of the parents did become emotional at some point during the interview, and a break was offered to each of them. However, none of them wished to stop and I acknowledged to them their reaction to this difficult time seemed normal and expected. If any of the parents had agreed to needing a break, or postponement, he or she would have been reminded that opting out of the research was always an alternative. Third, and following from this potential situation, it was important to have accessible and reliable follow-up mechanisms in place. I left my contact number with the participants and encouraged them to reach me with any concerns. I had planned to contact anyone whom I felt was left upset by the interview; however I did not have this sense from any of the parents. If the interview had been postponed or ended with the parents seeming very distressed, a follow-up phone call would have been made later that same day. I continued to be available to the participants during and after the interviews. If the need for more therapeutic intervention had arose, referral to proximal and affordable opportunities for this would have been made.

Informed Consent.

Free and informed consent is a complicated matter when using qualitative research methods because the nature of the research emerges throughout the project. That is, specific interview questions are influenced by the direction of the interview as it takes place, so asking for consent to ask these questions prior to the interview is impossible. Research decisions may then be made based on data as it is collected. So, fully informing participants of risks is not possible, as the researcher is not able to predict the risks of all potential harms. This was partly addressed above, by adding statements to the information letter and consent form indicating that in fact, certain harms are possible and should be considered when providing consent. For this study, the notion of consent was expanded to a continuing process, verses a onetime decision. Byrne (2001) notes that "informed consent infers the past tense or a completed process" (p. 402), suggesting that all information is known and explained before the research begins, which often occurs in quantitative studies. She suggests that it is the responsibility of the researcher to ensure a dynamic informed consent process that is adapted and informed by changes in the study (Byrne, 2001). At the time of initial contact, as much as possible, the potential risks and benefits were explained to the potential participant as well as an explanation that consent is considered to be ongoing. Before each interview, consent was revisited and formally received, in order to provide the participants with the opportunity to reconsider their participation. If any of the interviews had been interrupted or postponed because the participant became perceptibly upset, consent would have been revisited again before resumption or recommencement of the interview. (Appendix C).

Confidentiality

Another risk to the participants was the loss of anonymity and confidentiality. All research participants have been given a pseudonym when referred to in the research text and assurance of confidentiality and anonymity, except when prohibited by law, has been given in writing to each participant. As well, identifying details, such as gender of participant or diagnosis of the infants may have been changed in order to further protect the identity of participants. The risk to anonymity will be clearly stated in the consent form, as well as discussed with potential participants. Human studies must always attend to pursuing knowledge and increasing understanding of the human condition, while never failing to take into account what is asked of participants. Bergum (1991) confronts this concern with validity when she asks "When you become involved in your [qualitative] work, the ethical issues become "how are you true to…the [participants] you work with, true to their words and, yet, never hurt them in any way?"(p. 54).

Full Potential of this Study (Including Limitations)

The specific findings of this study are limited to the experiences of the parents who participated, and perhaps others who are similarly situated. The value of this work and other qualitative research is that it increases our understanding while alerting us to the endless possibilities inherent in any human experience. I recognize that the main limitation of this study is situated in my ability as novice researcher to capture the experiences of the participants in a rich and deep way. During this work, I asked myself continually – Can I go deeper here? Have I expressed this well enough? In order to mitigate this limitation somewhat, it is best to see this work as not yet fully realized, but as a work in progress. Understanding could always become deeper and the interpretation more vivid and clear.

CHAPTER FOUR

Findings

These 'findings' are the result of the thematic analysis of the participants' descriptions of their experience of having a child in the NICU. I have attempted to elucidate the meaning of their words through four themes including: *walking into an alien world, feeling vulnerable; becoming vigilant, going home at night: trust in the NICU*, and *coming face to face: please see me.* These themes are presented here as discrete entities in order to explore the experiences of the parents. Of course life as experienced by human beings does not happen in separate segments of vulnerability, followed neatly by an experience of trust. The experiences named by these themes do not exist separately. They may happen at the same time, in varied nuances and in different sequence, all in a rich and chaotic way. Indeed, the experience of becoming or being a parent to the child is not recognized as a theme, but is foundational to the entire experience of these parents. Support, or non support given by the health practitioners of this interrupted, but morally crucial and still-developing relationship is implied through all of the themes. During the process of analysis I questioned and puzzled over where certain descriptions and accounts of the parents actually fit. For example, words that originally seemed to be speaking about vulnerability could also show the desire to be recognized as a person; descriptions of a parent's reaction to the unit might also reveal their choice to trust. Ultimately, the final choices of one theme over another were my interpretive choices. They are ways to bring attention to what I have found in the parents' words. As Bergum (1989) suggests, it is best to regard themes as "useful focal points, or commonalities" and, it is important not to make too much of themes, as they might be different (p.13).

Walking Into an Alien World

Aliens Have My Baby: Walking into a Spaceship

Neonatal intensive care units are places that most people never see, but among those who share the experience is a fairly universal initial impression of the NICU as not only an unfamiliar place, but a completely different world.

> *So, the first time when I walked in, I felt like I walked into* [a] *spaceship. It was so, I felt lost, and I felt like he didn't even need me. That's how I felt; his life relies on all these machines and all these people here, not on me. I was afraid to touch him, I was afraid to disturb anything, I wasn't sure if I should even be there*...(Maja Delich)[3].

A parent's first walk into the NICU is an overwhelming experience. At the core of the experience is the knowledge, both bodily and intellectually, that one's baby has been born too soon or seriously ill. It's a surreal understanding that what is happening is wrong, out of order and deeply unexpected. Whatever the anticipated moment after the birth of a child might be, as seen in movies, witnessed in the lives of friends, as experienced previously or even as imagined by ourselves: it is not this. It is precisely not being separated from your baby, it is not wondering if the baby will live, it is not, as these mothers describe, wondering if you, the mother, should *even be there* and it should not include wondering *if she was alive or what was going on*. Christine Hayes, mother of two children born at term before she had her premature twins reflects on how this experience of pregnancy and birth was so coloured with worry.

> *even the day they were born, that was not an exciting day, because, my husband and I were just talking about it the other day, he didn't look at them taking the baby out...he didn't want to look because he didn't know if they were breathing or if they were about to die, or... it's very, very strange the feeling that you get. It's not the excitement of a birth.*

Before birth, fathers and mothers have known their child during the pregnancy, they are not strangers. But for the parents whose child is in the NICU the first face-to-face moments of meeting their baby happen with their hearts heavy with the fear of what will come next: the possibility of losing their child.

As the door opens, the new parent hears multi-tonal beeps and sees people moving busily, perhaps bent over the small babies on open beds, or rushing to get some supply or medication. The babies themselves are hard to make out, hidden by ventilators and IV pumps around the bedside. The lights are bright, there are machines blinking and tubes draped everywhere; the air is alive with energy and purpose. Often it is the father who enters first, while the mother recovers from birth; he has left her to come here. Although most of the parents describe feeling afraid on this initial visit, one father participant, Ivan Delich, describes feeling calm, and as though the *worst was over*. It is as though, during his wife's premature labour he focused on whether or not his baby would survive delivery, and had not yet adjusted to the new reality of a living, but still very critically ill premature baby. At the moment of entering the NICU he felt calm and relieved that the baby was born and alive, acknowledging that at the time he had no idea of the long months ahead. At the time of that first visit, the baby was alive and he describes that *when it happened* [the baby was born and moved to the NICU] *at that point... it was kind of calming*. He was reassured by the competence of the staff, evident as he watched them looking like *we know what we are doing here*; along with their demeanor *they were not sad* which gave him a sense that things with his baby would be all right. He describes later realizing that after admission to the NICU, *you don't have time to think about anything else. It's just him and the scary battle and you have to be there* (Ivan Delich).

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[3] The words of participants are in italics. Quotations are verbatim, except where filler words (For example: uh, um, you know, like) have been omitted for ease of reading.

When the mother enters the NICU, she has yet another layer of experience. She has just given birth, often in a way that was traumatic and unexpected, and is still feeling the physical changes, discomfort and pain that accompany both vaginal and caesarean birth. Most often, she received only a quick glance at her baby before he was whisked away to the NICU. She may enter the unit in a wheelchair, with the hormones of postpartum beginning to course through her and perhaps also feeling the effects of pain relief and other medication. For a newly postpartum mother, just getting to the unit may not be easy or straightforward. Christine Hayes remembers trying to get from her boarding room where she was staying to the NICU to see her babies, just a few days after the birth of her twin babies.

> *The day that I actually was discharged, I couldn't even walk. My stitches had come apart and I had a big gaping hole and they had to re-stitch me, it was horrible... I was staying in the boarding rooms and it's quite a walk...I remember looking down that hall thinking how am I going to do this? And I think a lot of my anxiety at that time was* [thinking] *I don't know if I can do this. And you never feel more alone at that moment...I felt like no one really cared.*

On this visit, Christine would have entered the NICU to be with her babies feeling alone and uncared for; yet another layer of complexity on her experience.

Maja reflects on feeling out of place and unsure in the NICU on her first visit: *especially after, you know how it is after birth, those hormones, you cry ...and I was taking Tylenol 3 which - I was totally retarded, I realize that now.* In retrospect these mothers realize that their initial experience of the NICU, and of their babies outside of themselves, was influenced by both physical changes in their bodies as well as medication taken for postpartum pain. Christine Hayes describes the enormity of feeling and experiencing all of these things at once in the early days of her twin babies' admission to the NICU:

> *I was very emotional at that point, hormones for one thing, I just couldn't stop crying and knowing that you just didn't know whether they were going to survive and then it's intimidating walking in there for the first time and seeing all these, you know, they're hooked up to everything and the bells and the whistles going off all the time...*

Indeed, the complete *sensory overload* contributes to and is the backdrop for the emotional reaction of the parents upon entry to the unit. Kate Myers describes walking onto the unit and feeling that her every move was observed, as she saw her daughter for the first time and began to comprehend what it meant to have an extremely premature baby:

> *other families and people are looking at you and the nurses are looking at you, and everybody's watching, and you have this little baby –she was 1 lb 10 oz when she was born, and she was underneath the warmer or whatever, and it's just like sensory overload. And they're telling you not*

> *to stroke her and you're scared to even touch them and just everything, just the shock to your system...*

John McDonald describes the experience as *probably one of the most stressful things to go through.* His wife Jamie describes feeling

> *bombarded by non-medical staff. The breastfeeding nurse, the pastor, all these people who the next day I probably would have, I would have wanted to talk to them. I did not want to talk to them* [during admission]*... I had to ask the breastfeeding nurse, please go away; I can't talk to you about this right now. I want to talk to this nurse and doctor about my baby.*

She acknowledges that during their time in the NICU she observed that often, if the allied health staff did not meet and talk to the parents on that first day the parents sometimes missed out on the service. However, for her it not only seemed like too much, these discussions seemed irrelevant at the time when all she cared about was whether her baby was going to live or die.

Even long into their NICU stay Jamie and John McDonald are reminded of the difficult and painful first few days every time they watch a new family come into the NICU. They recall asking each other if that *glassy-eyed look*, the look of *horror* that they see on the faces of parents entering the unit for the first time is what they looked like when they first came into the unit. Jamie refers to the difficulty of witnessing the first experience of other parents when

> *a new mom was coming in to see her baby for the first time and I would imagine that's what I looked like – she was crying and I would have to get up and leave because it was too painful to watch a new mom coming into the NICU, for me anyway.*

Her own memories of the first days are experienced in her body and she is taken back to when she experienced the devastation and crisis that accompanied her own baby's admission to the NICU; to the point where she feels again the complicated and overwhelming despair, fear and worry of admission. It seems that Kate's feelings above of being watched as she enters the NICU are reflected in the memories of John and Jamie as they describe watching new parents come in. Do the watched become watchers; remembering, reliving?

For Shannon Wright the physical features of the unit seem less important. She describes nothing of the physical unit but remembers the people of the unit, her new daughter and the nursing staff. She describes seeing her daughter after she returned from surgery, *all I remember is she laid there with her breathing done by the machine and it wasn't nice to see*…[starts to cry]. She then goes on immediately to talk about the nurses who looked after her child the first few days. Shannon was the only parent in the study who gave birth to a term baby, Beth, who had been diagnosed in utero with a serious but treatable physical malformation of her abdomen. Very soon after birth Beth was taken for surgery and returned to the unit in a medically induced coma and dependent on a ventilator for her breathing. Shannon remembers a nurse who took care of Beth after her surgery and describes how she appreciated the reassurance she gave to her, as Beth's mother.

> *We had her, that was the start of her shifts and we had her for four days* [in a row] *and just amazing all around, for her. I don't know, she just made me feel comfortable, like I bawled every time I came and every time I left and she just said "she's doing good" and let me know what was going on and she visited with us and kept us up to date with her.*

Pace of the NICU

Nurses and other practitioners in the NICU move quickly. The neonates are critically ill, with multiple treatments occurring at once and emergency situations happening as relatively routine. I recall working shifts where I quite literally ran to retrieve supplies or to help a colleague. The parents of this study recognized how busy the staff members of the NICU were. They were respectful and understanding of this, forgiving and justifying even, in many circumstances. However, they did not appreciate being 'put off' when they felt they were asking for something they considered reasonable, particularly in regards to the care of their baby. Shannon Wright describes returning to the unit with her husband after supper and seeing that

> *she had vomited all over the side of her incubator, and it was dried on so by the time we came back, I mean we weren't gone for that long, but obviously they hadn't heard her or checked her or anything. That kind of made me upset.*

Jamie McDonald describes coming

> *into a situation where Ali is crying in her bed, her arm is swaddled down both sides and her crib side is down. Not up. Not that she's going to roll out of bed, but the potential* [exists] *for her to. I come into this situation, and I'm just vibrating: "What's going on here?" And she* [the nurse] *came to us, "Well, I went for break and I have other children, and it's perfectly acceptable to swaddle her arms to her side." And I'm like, "Guess what? It's not acceptable to me!" I understand you have other children, I understand maybe you can't hold them, but give her a chance to soothe herself.*

Jamie acknowledges that there are competing obligations for the nurse, particularly when her baby is one of three or four in an assignment; however she is angry because she feels her baby was not treated fairly, not "given a chance". It is not the care she believes her baby deserves.

Ivan Delich explains that

> *I think the number one for everyone should be the child. I wouldn't really be asking so many questions if she* [was busy with] *my child, I would wait for her until she goes and sits somewhere in her - do anything else and I would ask...Because he's the primary goal. And I think that's the most comforting to every parent to see; that the child is being well looked after.*

It is not only the care of the baby that can be jeopardized in the eyes of the parent, but, for some, also their own. After spending the first week at one hospital, Shannon Wright's baby Beth is transferred to another hospital to recover. Describing herself as 'hating change', Shannon tells of her experience at the new hospital:

> *so I went there and found my baby and then I asked, I needed to pump, so I didn't know where anything was, they didn't really tell me when I first got there. So I asked one of the nurses, because my nurse had gone on break, and she was like "I don't have time to deal with this now" so I was just bawling, because first of all everything's brand new to me and this nurse was a little bit of a bag.*

Not having time to deal with someone's request may be a very legitimate situation in the NICU. However, what Shannon Wright is hurt by here is feeling as though the nurse does not have time for her. The parents in this study seem to understand that there are priorities of care in the NICU; that orienting a mother to the unit may have to wait when there are urgent care needs of someone else. But, it is important for this nurse to understand that the way she conveyed this to Shannon at that moment influenced her deeply by hurting her. Is there a way to relay a real shortage of time that does not jeopardize the requestor?

Further along in the admission of her baby, Eva Carter has come to know the daily routine of NICU care and strategizes about when is best to ask questions.

> *So if I could see that they were busy and I had questions, sometimes I would just wait until they weren't busy. I got to know the pattern of breaks so I wouldn't start asking them questions when I knew they were about to go on their break, or when they had to do all their numbers...why start asking questions right then?*

Eventually, she realized that parents were allowed to read their baby's chart. Once she began to do this, she felt more self-sufficient and reserved her questions for those not answered in the daily notes. *The whole, oh were there any changes today? Why ask them, when I can look for myself?* Eva's description of her increasing comfort and familiarity with the unit was reflected in the words of the other parents who had lengthy stays. Becoming comfortable and familiar with the unit was reflected in the changing attitudes of the parents as their babies' stay in the NICU progressed. Their world became a little less alien as they began to learn the language of the NICU.

Learning the Language of the NICU

As time in the NICU progresses, the parents' increasing acceptance and comfort in the unit is made evident by the language they use as they discuss their experience. They refer to medications by name and effect: Pavulon, Lasix, Morphine. They understand the schedules of the nurses, knowing when to expect shift change and dealing with that: *for us it was always, okay, who's coming on at three, because we always wanted to know. Who's coming on at three?* (Jamie McDonald) They know that when the 'bells' go off in level 3 it is more serious and the nurses respond quicker than in level 2 where the nurses check to see if the baby is *just wiggling* first. (Christine Hayes). John McDonald notes how the nurses begin to recognize and rely on the parents' knowledge of their baby as time progresses. *You know what's funny though is you could see the progression in you being there because eventually they'd start asking you questions, "When did this happen?" or "What was she like on this day?"*

Language is how we learn about the world we are in, and as parents begin to be familiar with and use the expressions of the practitioners, they are learning more than just words. Ivan Delich describes one nurse's care-giving as not what he expects and not what he is used to: *She comes and checks her numbers and she goes. And then again, she comes and checks her numbers and goes – never looks in* [at] *the baby?* The parents describe coming to know the language and routine by being at the bedside, watching for hours at a time. Kate Myers suggests this information not have to be deciphered by parents:

> *I talked to the social worker before we left and we were talking about how it would be good for parents to get an information package when they go in, because there is so much there. And even, what are you doing, what are blood gases, and that kind of stuff and "what is this tube sticking down her throat and when can it come out" and "what is a CPAP machine" and, that kind of stuff, because the lay person knows nothing when they come in there.*

A central structure for managing the medical care of the babies in the NICU is morning interdisciplinary rounds. 'Rounds' refers to when the entire health care team[4] walk from bedside to bedside assessing the plan of care for each baby, the most comprehensive of which occurs in the morning. The parents in this study refer to learning the importance of rounds. Ostensibly, and by policy, parents are welcome to be at the bedside during rounds. The level of participation actually sought is less clear to the parents. Many subtexts occur here as observed by Jamie McDonald. *The first time, that round, they did rounds with their backs towards me.* She describes they started to include her as *well, my voice got louder as we got through the experience, however, I mean I was just, 'Okay, this is my baby.'* Over the course of time, she notices that because the attending neonatologist (in charge of the medical care of the babies) would change every two weeks, she felt it *was like I would have to start over with the neonatologist in terms of, 'Guess what? I'm an involved parent.* Having to assert her role as mother repeatedly caused her to reflect on the expectations of the team:

> *So, some* [physicians] *were better than others in terms of letting me be involved, but I mean, the other team of people knew that by then because the dietician was the same and the charge nurse was the same and the pharmacists were the same, so I just remember thinking... maybe they're not used to parents – maybe I'm not supposed to be here or, I knew I was supposed to be here, but I didn't feel welcome...*

Rounds are routine opportunities for specific discussion about a baby's condition, general teaching of students and staff as well as the formal structured time to plan care for the babies. Christine Hayes describes walking up to rounds shortly after they had begun on her baby and overhearing a discussion about medication:

> *they were talking about caffeine and these different medications that they were on, what they do to the brain and they were saying, the way he was*

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[4] The health care team may include all or some of the following: neonatologist, charge nurse, respiratory therapist, dietician, social worker, nurse practitioner, neonatal fellow, resident, pharmacist as well as the registered nurse at each baby's bedside, and perhaps others.

> *describing it, was really they don't know how it affects their brain and how it can, basically in a layman's terms, kill off brain cells.*

She found the conversation *really unnerving, because I had sort of, you know, been reassured that these were safe medications* and walked away from the bedside crying. It is hard not to wonder how the conversation about adverse effects of medications might have transpired if Christine had been at rounds from the beginning and the staff were aware of her attendance. In this instance, another physician noticed what had happened, followed her and by acknowledging what had happened and going over the effects of the medications, greatly reassured her. Did this experience influence how she interpreted other information given her by the NICU practitioners? Jamie and John McDonald are aware of the possibility of not receiving the full picture from the beginning and reject it outright:

> *To think that you're going to discuss the care of our baby...they discussed it amongst themselves, and then we were given 'the version'. I don't want 'the version,' I want all the nitty-gritty details about the TPN* [Total Parenteral Nutrition – intravenously administered nutrition] *and all that.*

Shannon Wright, whose baby had the shortest stay of any of these participants (just over two weeks between both units), was not always able to get to the unit in time for rounds, and had the impression that, *well they would come at all different times.* She refers in her own way to not feeling welcome or as though she has a place at rounds: *but, even if I was there, I didn't know who was who* and suggests her non attendance at rounds as the reason she did *not have very good relationships with* [physicians]. Shannon's shorter stay on the units may have contributed to her not knowing when rounds were and not perceiving their importance in the same way as the other parents. Ivan Delich suggests that as time passes and parents become more familiar with the peculiarities of time and routine on the unit, rounds are perceived to be essential when he says *Oh we didn't want to miss them.*

As the parents learn the nuances and meanings of what is happening to them, they acknowledge some ambivalence as they come to more fully realize some of the implications of caring for critically ill babies. They see that the treatments themselves, in turn, can cause problems. Ivan and Maja Delich discuss how this affects them as trusting observers when their baby is very ill. Ivan describes his uncertainty.

> *Sitting there and watching there,* [seeing that] *they are helping him, I am conscious about that, but also I know that's damaging him.* [Looking] *on it the other way; you know I am conscious about that and it's tearing me apart. And I'm sitting there.*

His wife agrees,

> *yeah, it's hard to look, he was* [being saved by] *the ventilator, but the ventilator at the same time is causing him damage; he is getting morphine to help him, but at the same time you know there is some* [serious side effects*], he was on steroids, like all those drugs, but he is not even supposed to be born and he is getting all that stuff, what is his life going to be like? You start to ask yourself questions.*

They began their NICU experience feeling like everything was totally alien; now the parents have gradually become familiar with the unit, and as they become part of the unit they seem compelled to ask, what will this all mean for my child?

Home is Where the Baby Is

After the initial crisis, the NICU becomes part of the routine of the parents' lives. Going to and from the hospital dominates life; organizing visits and planning times to do care provide the structure around which all of one's daily activities are organized. Different situations shape this routine differently. For some, this means getting to the unit each morning to attend rounds, participate in bedtime or both. Others stay at the hospital for days at a time before returning to be home with their family, far from the city, for a few days. Christine describes parents finding hope in the journeys of other parents before:

> *you saw a lot of positive things, especially the graduate board or, they have binders of babies that* [show] *'then and now' type thing. So that was*

> *huge, and everyone, every single person that goes in there, the first thing they do is go to those books or that graduate board.*

These albums and boards show pictures of NICU infants at birth, when they are tiny and ill, beside a picture taken at discharge when the baby is bigger, often chubby and, perhaps most significantly to the parents, going home. These parents described their long NICU stays as eventually characterized by a certain level of comfort and familiarity.

> *Other relationships that you develop are the ones with the receptionist, because you see them every day, or three times a day. At first I was a little put off with, how can I say it, you were kind of just let in and out. But obviously the longer I was there you got to know their names and you got to know who they were and actually just before I left, you're on a first name basis. Or, you'd phone her and see how the babies were doing if you were at home and they would chat with you for a minute. But that, I mean that was there because I was there for a long time. I don't know if other mums that were there for you know a couple weeks or three weeks would experience that.*

Comfort with the unit would sometimes be related to meeting and becoming close to the only people who really understood what life as a parent in the NICU was like: other NICU parents. Kate Myers describes burgeoning friendships with other parents:

> *myself and the other mom would play Backgammon, because we were always next to each other. Because your baby is sleeping, and there is really nothing you can do for your baby. You want to be there; you don't want to be anywhere else. And, getting together at the Bear's Den* [parent lounge] *with the other parents, and just goofing off or whatever, and going downstairs for supper. We were also there for each other when things got sad, you know, when* [one baby] *had to have a shunt put in and stuff like that, and when the one little girl had problems with her feeding and couldn't eat. We were always there for each other. And so that was nice – you knew you were there for each other.*

This group of parents who became close acknowledged the NICU slowly becoming a home of sorts, as the concept of home became inseparable from their baby: [the place to be] *was with her, and that's what me and the mums that we got really close to would always say, home is where the baby is, it doesn't matter.* (Kate Myers).

Maja Delich recognizes an inherent tension that exists as discharge approaches. An important goal in the NICU is to help the parents become comfortable in the unit and with the care of their baby. We have seen in the earlier discussion of the literature and as evidenced by the parents in this research, the NICU begins as a strange and unfamiliar place and gradually parents see it as less foreign and begin to identify with the unit as a place in their world. They become comfortable, play backgammon, joke with nurses and come to know their baby and themselves as parents. During her family's experiences on the unit during the course of Nicholas' life there, Maja describes feeling *like I'm among family,* and yet acknowledges that *the worst part, the saddest thing is once we are discharged we can't come back and close that door, you know?* She feels that once they are discharged the relationships are, in a sense, irretrievably lost. Of course, she wants to be home with her baby, to move on to the business of getting on with this family. And, she knows that once discharged you cannot return to the unit in the same way because you no longer belong.

> *It's like they are tossing you out – you can come to visit but still, if I want to see all the nurses, then take him and say hi and talk... So that was hard, but of course every single parent can't* [return to the unit], *all the kids would be crowded, it's understandable it's life, that's life. But, I mean we've spent so much time there and we've met such great people and you know they took care of your child and you won't forget it all your life.*

Christina Hayes refers to entering the NICU by saying *nothing really prepares you for it.* As I heard her say that in the interview and throughout countless readings of that line from the transcript of my interview with her, I thought she referred to the initial experience of the NICU, the noise and intense energy coupled with worry over your child's wellbeing. Could she have been referring to an even richer and more complete description of the NICU experience? Yes, of course, very few of us ever experience the physical reality of a neonatal intensive care unit and, thankfully, statistically few of us go through the experience of having a premature or ill infant. But not being prepared for something refers, by default, to what we are prepared for, which includes the culturally embedded expectations of childbirth, of parenting, of what life is 'supposed' to be like. We grow up, most of us, reflexively expecting to have a healthy term baby. Being a parent in the NICU profoundly and eternally changes how one sees the experience of becoming a parent and, in that sense, the world. Unprepared for the experience, the parents are in new territory, figuratively and literally, negotiating their way: they are vulnerable and become vigilant.

Feeling Vulnerable; Becoming Vigilant

Feeling Vulnerable: Left Alone With Me, He Would Die

In the NICU, the fundamental tenet of parenting, that is, *being* this child's mother, or father, taking care of her and getting to know her, is immediately placed in serious jeopardy by the baby's condition.

> *The hardest thing to realize is that your child has all these people and they - all of them - know everything better than you about him. If he was left alone with me, he would die. That's the hardest thing to accept.* (Maya Delich).

Here, Maja expresses the most basic vulnerability of each of these parents: they are forced to rely on others for the care of their baby. This initial impression is that they are completely unprepared and unable to enact their parental roles as protector and caregiver. Of course, parents do have roles in the care of their baby even in the NICU—only mothers can pump breast milk, their voices and touches, their understanding of the baby cannot be replaced—however Maja is right: left with their parents, these babies would die.

To be vulnerable is to be capable of being physically or emotionally wounded, to be open to attack or damage (Merriam-Webster Online, 2007). Vulnerability, being vulnerable, is a hallmark of parenting in general. New parents talk about the radical surrealism of loving another being more than oneself; of being left wide open to being hurt by just the idea of harm coming to one's child. Parents of healthy term babies are open to being vulnerable as they may wonder how to look after this little creature. How will I come to know this baby? Will he love me? Am I up to being the parent of this child? How can I keep him happy and safe for the rest of his life and at the same time encourage him to grow and become separate and experience life? Why is she crying? Being, and for some becoming, a parent in the NICU offers these vulnerabilities compounded and accompanied by many, many others. Here the questions start with: will he live? Can she breathe on her own yet? Will he survive surgery? When parents at home ask questions like 'does she know me' they receive some reassurance as they comfort their child, experience the first smile and become familiar with their role as loving caregiver to their new baby.

Even after becoming more familiar with the unit, the parents are easily reminded of their vulnerability through the fragility of this sense of comfort. In the NICU, babies are arranged in nursing assignments. The assignments are kept balanced, in terms of the needs of the babies, to provide the best and safest care. Practically, this means that they are often moved around so that the babies in one nurse's assignments are close together. These moves do not necessarily happen when the parents are present. Kate Myers describes her embodied reaction to not finding her baby where she expects her: *but you don't know that when you go over there, and you walk into the pod, and your baby's gone, and the spot is empty, and it's just – your heart just goes to your toes.* The mother asks out loud, where has she gone? Inside, before rational thought reminds her that she would have been told, she may be asking, is she dead? Without all the usual ways to become known to their child as mother and father -- holding, feeding, comforting, losing sleep – how can NICU parents find a way to know their baby, a way to being their baby's parent not outlined in books or storied in familial knowledge? The initial link between parent and baby is provided by those looking after the baby in the NICU, the nurses, physicians and other health practitioners

Nurses: Gateway to the Baby

In a very practical way, the NICU practitioners, and the nurses in particular, become the parent's gateway to their own baby, perhaps especially at admission and other times when the baby is most seriously ill. Ivan Delich remembers this process fondly *All those little things that they introduce you to they're just the precious things. And right now, thinking about it, it's just incredible.* His wife, Maja, is grateful for this help from the nurses as well, but worries still that her baby might suffer because she did not know what to do for him. After being told, on her baby's fifth day of admission, that it is better for premature babies not to be stroked, but instead touched with a still hand, she worries that for five days she had not touched him properly.

> *It's just accusing yourself, feeling guilty, that's how you feel after. I guess I remember myself when my mother died. I felt guilty and just trying to accuse myself, oh I was doing this wrong...because that's the same thing, if something goes wrong I was feeling guilty because I didn't do, you know, five days ago if I had started doing this maybe that means something to him. Maybe he is going to miss something, but it's not actually, he doesn't know what he would miss.*

Even as she reassures herself now, in retrospect, that the way she touched him the first five days will not have long lasting effects, we see here how profoundly these worries were a part of her life as she remembered and compared her experience of not doing enough for her son with that of her mother's death.

Kate Myers did not hold her firstborn child for sixteen days. She refers to a nurse caring for Julia during this time and how she mitigated the loss Kate felt not being able to hold her child.

> *Every time that she was working, she would let us do as much as we could with her. She would let us give her a little sponge bath inside her isolette, and try to let us change her diaper even . . . , or when she was turning her over, she would let us hold her* [up while she was] *changing her bedding. She just . . . she put it in our hands.*

What may be most meaningful here is that this nurse supported Kate to be a mother, to know her baby. Her support of Kate is enduring as she recalls how much this meant to her months later. However, it was also an arbitrary, tenuous gift. This education and encouragement, these ‘permissions’ to be a parent to one’s baby in the NICU remain a source of vulnerability for the parents, because they may be revoked by another nurse at any time. *A lot of other nurses would say, Oh, no, you can’t do that. And well,* [I would think] *we’ve already done it.*

Maja and Ivan Delich describe a similar situation where they had been doing, as they describe, *literally everything* for their baby. Nearing discharge they are nearly independent in taking care of him while they are in the unit during the day. They describe feeling confident and Maja describes how meaningful it is to her to take care of him: *the more I did around Nicholas the better I felt. The less help I received from nurses the better I felt.* One day a nurse who has not looked after them recently comes on shift and is taken aback by how much Maja and Ivan are doing and tells them *“I don’t know if it’s right, the parents doing this* [care].” Maja believes she said this because the nurse did not like her. The incident is resolved by the charge nurse who confirms that it is all right for Maja and Ivan to continue with the care they have been giving their baby. They are shaken and their vulnerability is confirmed by their experience. They describe their perception that parents are very much subject to the whims of the nurses, to the individual beliefs regarding appropriate levels of parental involvement, but also subject to the nurses’ own personal feelings about the parents. This perception is made all the more potent by the sheer number of different nurses involved in the care of one baby over the course of three or four months. Maja is incredulous as she says that even [on the] *last day we were meeting new people.*

Sometimes, nurses are not just the gateways between parent and baby but actually gateways to finding meaning in the experience. Kate Myers describes how tough it was to see her tiny, fragile baby daughter with translucent skin and fused eyelids. In conversation, one of the nurses told her that being in the NICU is one of the most stressful experiences one can have.

> *And that's the thing; it's knowing that what you're feeling is not bizarre and it's not strange, and that you're not stupid for feeling the way you're feeling. That it's totally expected, and normal, whatever normal is. That really helped – to hear that what I was going through was* [okay].

We might see this nurse as "bearing witness" (Naef, 2006, p. 146) to what Kate was experiencing. By using her experience and knowledge she was creating moral space where Kate could reconcile and live with her experience. Bearing witness is less a way of rationing expertise and permission, and more a way of being with another in the moment, of listening to what they are saying and of staying with them (Naef, 2006). Being with the parents as they experience the complicated, layered vulnerability of being parents in the NICU calls for supporting the parents as parents. Maja Delich suggests

> *when the parents come for the very first time to see the baby, for me it would be comforting* [to know] *what directly I can do for my baby. Like, if he's so small that I'm afraid to touch him, to tell me right away that he's not going to break, that it's going to give comfort to put your hands* [on him].

Of course, all of the parents in this study spoke of looking forward to discharge, to taking their baby home, but none as single-mindedly as Kate Myers. As she described it there was one end to this experience that defined all else: getting her baby home. *That's the one thing that the nurses need to realize, that everything that you're doing there is to help you get home, and everything else just goes by the wayside – when can I get the baby home?* Kate and her husband joked with each other about taking Julia inside the isolette, *we had always talked about, we can take it and we can attach it to the AC adaptor in the car and we'll just go.* One night, her *husband had a dream that we were in the mall, and he was pushing the isolette,* as if it was a stroller, shopping. Kate explains how this defined her experience day to day in the unit.

> *Sometimes that kind of stuff was hard because they sometimes wouldn't listen to you. Like, I had one instance where I told one of the nurses, "I'm going to be back at two o'clock to feed her, and if you could wait,*

> *then I'll be here." And so, I came back and she had already fed her. And, so* [I said] *'I told you I was going to be here.' and she says, 'Well, you went for lunch and I wasn't sure,' and* [I said] *'Well, I told you I was going to be here.'*

As Kate explains, what bothers her is not as simple as missing one breastfeeding with Julia, but rather what that one feeding means at this stage of Julia's life and her own transition to being Julia's mother. More than a feeding, it is one more step in learning to assume care of her baby and to be her mother.

> *It's hard for the nurses to see that every time something is put off like that, you seem like – you feel like you're there another day. Do you know what I mean? You feel like because I didn't get to breast feed her there that time maybe it would have been another day* [longer until discharge].

Moments like these reflect much more meaning to parents than may be apparent to practitioners, who perceive it as just one missed feeding.

Jamie and John McDonald describe a moment that changed their course of care in the NICU for the better. At the same time, the experience caused them to reflect on the 'accidental nature' of the exchange. Jamie describes sitting next to the isolette one Saturday near the beginning of her daughter's stay and feeling helpless, sad and disappointed at not being able to hold her or help her in a tangible way. Then, her nurse *comes along and introduces the concept of NIDCAP*[5]*, introduces the concept of primary care – just in ambient conversation – not in any of the structured information you find in the unit...* This piece of information deeply influences the McDonalds' stay in the NICU; beginning with the sense of purpose given to Jamie at that moment:

> *all of a sudden, we grasp onto it, I grasped onto it, I need more information about NIDCAP, I need more information about primary care. All of a sudden I feel like there is something I could contribute, we*

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[5] NIDCAP is the acronym for Newborn Individualized Developmental Care and Assessment Program. It is a "relationship-based developmentally supportive approach to newborn intensive care" (Als & Gilkerson, 1997, p.178; see also Westrup, B., 2007)

> *could contribute to Ali.* [It was] *the first time I felt, I really think, that we felt really, really involved.*

This nurse's remark eventually led to Ali being enrolled in the NIDCAP program, essentially meaning she received more developmentally appropriate care, including increased engagement by her parents as they learned about and participated in the care. The process of NIDCAP changed how they felt about their parenting in the NICU and how they related to their baby. For example, they explain how the physician involved with NIDCAP explained alternatives to medicated sedation. It led to a wholly welcomed and life-changing experience for this family. However, even as Jamie describes *feeling energized* after realizing the possibilities this revelatory comment held, she acknowledges also a feeling of accidental luck. She understands that if that nurse had not been on that day, if they had not been with Ali, they would have missed out on the information that transformed their experience*: if we wouldn't have had that nurse that day we probably wouldn't have known about it.* This feeling is reinforced by information they received from other parents in the NICU: *whereas I talked to other parents and they had no idea how to get a primary nurse team together.* They describe learning about NIDCAP and primary care in this way felt like they had an unfair advantage over other parents.

> *There were two babies in there that were NIDCAP at the time… we were one of them because we sought it out. We sought it out for Ali because it was an opportunity for Ali, so it's almost not fair, it's almost not fair.*

Jamie and John McDonald are acutely aware of the difference that this moment of disclosure in casual conversation made in the lives of their family; of how vulnerable they were to missing out on this opportunity, as reflected in the lives of the families around hers.

Being Afraid

There is a great deal of fear in the parents' descriptions of being in the NICU. Fear over what has happened, what might happen and even the baby herself. *…I just couldn't. I was afraid of her…I was afraid for her and then there were all these people trying to talk to me.* (Jamie McDonald). Christine Hayes describes fear as an automatic association to the NICU: *obviously the first thing would be, it's quite scary at first, because NICU just to hear the word is scary.* This fear seems necessarily related to the risk of death to their baby but this is to some extent not directly spoken by these parents. Maja Delich describes the vagueness of fear in the NICU:

> *You can't believe that something bad can happen. I mean you are afraid, but still you don't accept it. Like, he was so sick and his life was so critical and we still didn't realize, not realize, but I don't know...we didn't think about him dying, like, not even...I wasn't afraid of that, I was afraid he was sick and that's it.*

Later during this critical time her husband, Ivan Delich admits that the thought of their son dying did cross his mind.

> *There was the one point that she had to go pump... and it was just agony. It was just agony. He was on Pavulon* [neuromuscular relaxant that "paralyses" the baby to aid ventilation], *lying down lifeless in that incubator and she said I have to go pump. And it's like in the second, just a thought, you know, why are you going to pump? Look at him. You know? I felt so guilty, just even thinking about that, just for one glance of a moment that he could be dying and why are you going to pump?*

Fear is an innate response in human beings, generally thought to be a self-protective emotion. As we become aware of danger or perceive some risk, fear alerts us to take action, to defend ourselves physically or to remove ourselves from the danger by running away. Fear and vulnerability are related, because as one becomes more vulnerable, more open to attack, one also becomes more afraid of being attacked. When the parent of a newly admitted baby walks into the unit, do we recognize them as being afraid? We must ask how it feels for parents who enter the NICU afraid; feeling their bodies and minds urging them to run away, when in fact they are at the same time *compelled* to enter, to protect and seek out their child.

✓ Eva talks about fear in a different way, she describes feeling she was *being scared* by health care practitioners in the NICU during her initial discussion with them about Aaron's prognosis. She describes her first visit (delayed three days after he was born due to her own health issues) to see her son where she burst into tears upon seeing him, so small and looking like he was not going to survive. She says

> *and they didn't give him a great prognosis, either. They had told me that it was about a 50-50 chance of him surviving, and even if he did, there was a 70% chance that there was going to be something really wrong with him...Oh I know* [they have to tell me that], *and in a way it's kind of, I felt like I was being scared.*

Eva speaks of distancing herself from her baby and the nurses early in the NICU admission *I guess in the very beginning, I tried to be...I guess in a way stand off-ish, 'cause I didn't want to get too attached to them if he didn't make it.* She describes her visits as short because being with her baby caused her to face her worst fear: his death. *I found it hard being there sometimes, 'cause then it made me think at the time like he's not going to make it. And so then that was upsetting, so sometimes I'd stay away for that reason.* She worried that this was not understood by the nurses and that they judged her for not being there enough.

> *I guess sometimes when I went in I felt like they were judging me. I'm not necessary saying they were or they weren't or anything else, I just felt that way. Like they were judging me 'cause I was hardly ever there, that could have just been once again, my guilty conscience.*

Eva describes her decision to not visit for long as a way to deal with her own vulnerability:

> *I'd only come in for an hour and I'd sit there and stare at him and put my hand on him. Part of me felt really guilty that I wasn't there longer like some of the other moms, and another part of me was just like, no, why should I? I'm doing what I can, I'm for him at times, but at the same time, I can't actually do anything for him. I might as well go home, go out to a movie with my friends and enjoy my life because if he does make it, then I'm not going to have much of a life after that. And if he doesn't then I have to try and pick up the pieces afterwards.*

Eva is conflicted, wanting and not wanting to be with Aaron. Is it fear that keeps her away? Is she afraid of both 'having no life' if he comes home and at the same time of having to 'pick up the pieces' if he dies?

Christine Hayes protects herself in a different way. Although she is there, in the unit, she describes how she deliberately controlled her emotions, and how it was hard to let that control go even after discharge, at home.

> *I found emotionally that you try to be somewhat optimistic, you don't want to allow yourself to be too optimistic, but you don't want to be down in the dumps either, so you tend to be on a plateau and you just wait for things to happen. And I found that actually I geared myself so much that way while I was there, that even at home I had a huge, huge, even though they were home and everything was well, I didn't know how to really adjust my emotions to happiness.*

Ivan Delich approached the unknown situation by seeking information himself, by asking questions. *And the nurse would* [answer] *me and the next moment I would ask the same question again. You know, because I wasn't sure what that means?*

Ivan describes needing and wanting to learn everything he can about the care of his ill child. Yet, he does not understand what he is being told. Like any parent anywhere, he wants to watch over his baby, wants to protect him as much as he can, but because of the situation, he does not know what to watch out for.

Becoming Vigilant: What Am I Watching For?

As parents, we keep our babies safe by watching out for them. We ask questions, we do research about the best food and the safest toys and we learn, from our mothers, our doctors, our books and our computer what the right things are for our baby. It can still be complicated, but most of us usually agree on basic tenets: watch for choking, watch for falling, watch for fever, etc. The desire to look out for one's child is not so different for a parent in the NICU, except that being in such a foreign environment makes it very difficult to know what to watch out *for.* Jamie and John McDonald tell a story of when they were confronted by a situation with their baby that is very common in the NICU to the point where staff may forget the significance such an event has to parents. One day, during Ali's course in the NICU, they are told that she requires a lumbar puncture (LP). Jamie describes her initial reaction as saying *whoa, you know wait a minute! Excuse me, who's doing the procedure, how many have they done, what are the risks; we need to talk to a doctor.* As she recalls the story, she is actually laughing a little at herself as she remembers sitting down with the physician who was going to perform the procedure and asking him, basically *Who are you, what are your credentials?* She describes the physician as *wonderful, very patient* with them and remembers the discussion of the procedure and its risks after which John asked *how many of these have you done? He said it really calm, like, well I'm doing three today.* Both parents smile as they recall their relief coming from the realization that what was to them *so scary, and so personal, intimate*, was to this physician, wholly routine.

Not knowing what to watch for, what to protect the baby from, is particularly significant at the beginning of the NICU admission and regarding medical and nursing interventions that are outside of the parents' experience, as in John and Jamie McDonald's story above. However, parents whose baby had an extended period of stay of several weeks or a few months explained that although the NICU was extremely intimidating, their experience changes as time goes on. They do begin to know some things to be vigilant of and to watch for. Eventually, with parental involvement, care of the baby reaches a point where the nurses come to ask the parents about the progress and preferences of their infant, as noticed by John McDonald in the previous section. Asking the parents about particulars of their baby can show the nurse recognizing their knowledge about their baby. Jamie and John McDonald described being asked these sorts of questions as a mark of progress; these questions gave them comfort.

However, similar remarks can be made to parents, where nurses make known their own lack of knowledge in ways that cause the parents to be fearful. Maja Delich describes a time near the beginning of her son's time in the NICU when a nurse cared for Nicholas for the first time:

> *That nurse made me so worried and nervous because she was "I don't know him, I don't know him, I don't know him" like whoever comes to see what's going on, she would say "I don't know him very well, I don't know him" and you know it seemed to me like* [something] *really bad is happening, nobody is telling me yet because they are not sure, it was so bad that I wanted to tell her after – listen, please do not do this, it's the worst thing you can do.*

It may be that this was so upsetting in part because this remark was made near the beginning of their experience, before they felt confident in knowing their baby. So, at a time when they wanted (and needed) to trust that their baby was in good hands, and the nurse may have been only acknowledging the fact that this baby was a new assignment for her, they felt afraid and nervous about their baby's care. They perceived the nurse's actions as evidence of a worsening situation. Ivan expresses his frustration during this experience: *get to know him, read the chart!* These parents alert us to their experience in a way that makes clear they appreciate acknowledgement of their role and expertise in the care of their babies once they are comfortable in this role themselves. At the same time they do not want to feel the professional caregiver of their baby has abdicated knowledge of the baby, which may in turn make them feel acutely their own lack of confidence and ability to care for their child's wellbeing. The parents need the practitioners to look after their baby, and to look after them. Hall, Dugan, Zheng and Mishra (2001) suggest that "Because trust arises from patients' need for physicians, [and other practitioners as well] the greater the sense of vulnerability, the greater the potential for trust" (p. 616, brackets added).

Going Home at Night: Trust in the NICU

> In short, it seems to me that trust is most required exactly when we least know whether a person will or will not do an action.
>
> Virginia Held (1968)

Some of the most rewarding and affirming moments of my nursing tenure in the NICU were when the mother of the child I was caring for would tell me that she felt easy and comfortable going home. In effect, she was telling me she trusted me, literally leaving her baby in my hands. These experiences from my practice resonate in the words of the participants. Jamie McDonald describes her feelings when watching a nurse whose care she felt uneasy about. She would think, *you're not clustering her care, or you're not—you're just making us nervous and we can't go home.* She contrasts this with her experience of *90% of the nurses were where you could go, "Oh, yay, Cathy's on! I'm going home!" You know that she's, or your perception of that nurse, is that they were very capable.*

Further she explains that leaving the unit when Ali was being looked after by a nurse they had not met before caused her to go against her own fundamental parenting ideal*: if I didn't know* [the nurse], *I was nervous. Who's looking after my baby? I wouldn't leave my 20-month old with a babysitter I didn't know.* More difficult still, knowing and not trusting the care of a nurse made it nearly impossible to leave. Jamie describes the effects of seeing a nurse assigned to her baby after specifically and repeatedly asking that she not be assigned to care for Ali (in response to an incident where Jamie felt the nurse had not taken safe care of her baby). When she realized that it was too late in the shift to request a change, and not wanting to be *that parent that's always complaining*, she decided to change her plans so she could stay at the unit that day. What this meant to this family was more than a change in schedule.

> *It affects your whole life. For example, I wanted to go home that one particular day when the nurse was back and we had the discussion. I had planned to go home and spend time with my 20 month old baby.*

By having to stay at the hospital, Jamie felt torn between her commitment to and love for both of her two children, and chose to stay with the one whose care she was not confident about.

With a nurse who knows the parent and baby well, trust allows the parents to leave even when things are not well with the baby. Maja Delich refers to her primary care nurse: *Communication was totally well between us. So, I could feel even if he was sick so bad, you know I would feel comfortable leaving him with her anytime.* Kate Myers says *the only time that I went home* [out of the city] *was when a nurse was there that I could trust, like when the primary care nurse was there, I would go home, because I knew that she would be fine.* Kate describes trusting this particular nurse because she encouraged Kate and her husband to participate in the care of their baby even before she was well enough to be held. *And so I think that she put the trust in us, and then it was kind of reciprocated.* However, after witnessing care from a nurse that she felt deeply compromised her baby Kate Myers found leaving the unit one night very difficult and she stayed until one o'clock in the morning. Feeling unable to trust these nurses imposed emotional and practical consequences on the lives of these families. They were prevented from doing important things in the world outside of the NICU (sleeping and seeing another child) but not trusting also effects their internal world, as they become afraid for their child. Govier (1998) describes: "If we distrust, we are not at ease. We are fearful and suspicious and feel a need to close off, try to protect ourselves, or control the relationship" (p. 3). And, yet, as the parents enter the NICU we ask them to trust us, people whom they have never met.

NICU Admission: Trusting Strangers

Well, it's hard, because really, you're trusting strangers (Kate Myers). The parents' description of trust at the beginning of their babies' stay in the NICU is characterized in part by the lack of trust they felt towards the NICU and the caregivers. Jamie McDonald describes how she felt early into the admission of her daughter, Ali, and specifically during her attendance during multidisciplinary rounds that occur every morning. No one from the large group of people acknowledged her and the discussion was held with their backs toward her. *They didn't trust me. I didn't trust them, they didn't trust me. They didn't know what kind of parent I was.* And, Maja Delich recalls that during her first visit to see Nicholas in the NICU, she thought *he was going to die, I was so afraid. You know, they told me he was going to be okay, but I didn't believe [them].* At that moment, she simply could not reconcile her tiny, premature child attached to machines and covered in tubes with "being okay", no matter what anyone told her. To some extent, parents understand that they have no choice but to entrust their baby to the NICU, and therefore, trust the practitioners caring for their baby, because they themselves are unable to care for their ill or premature child. Even as Maja says she didn't believe that her child would survive, we might wonder if this was not simply and superficially a reflection on trusting the prognosis given by NICU staff. Perhaps it was also the more spontaneous expression of her deep and worried reaction to that which seemed impossible – the survival of such a small and vulnerable infant. Seeing any baby born four months too soon for the first time is a shocking sight, seeing your own born this soon, and mixed up with rapidly fading hopes and dreams, it might make it impossible to reconcile the visions before you with survival, no matter how any 'expert' tries to reassure you.

When parents first enter the NICU, there can be a sort of automatic trust that they bestow on the professional caregivers and the system of the NICU itself. Christine Hayes describes being awed by the milieu of the unit, feeling as though amazing things happen there:

> *nothing really prepares you for it, and while you're in it and still now to this day, you're so grateful and actually totally amazed as to what they can do and you wonder how do they figure this all out, you're just totally amazed...*

She refers to a basic expectation of trust immediately given to the staff: *you kind of take it for granted that it's their job and they know that they're doing and you kind of let them go to it.* This seeming leap of faith can run very deep. *What they say is religion* (Kate Myers). Often, in the case of premature infants, the baby's original due date is suggested by the NICU practitioners as a reasonable time to expect discharge. Kate says

> *we went home before her due date, like just four days before. So that was exciting. But some of the babies there didn't. And that was really devastating, because you know, that's the one question, like the first thing that you ask, as a parent, when you go in there, like "How long am I going to be here?" and "When are we going to get to go home?" So*

> *when these parents didn't get to go home by their due date, it's just devastating, because that's what you get told from day one.*

Parents hold on to more than the actual words, but also the implied meaning granted upon entry of the NICU. That is, a baby comes here to be saved. When a situation occurs causing the NICU practitioners to tell parents that they may not be able to prevent death, or do all that the parents expect and believe they can do:

> *It's hard to come to the point where you look at the doctors and the nurses like they can do* [anything], *they're going to save him, and then they tell you that they might not succeed. It's like the world, it's falling apart* (Maja Delich).

The belief that the NICU and the health practitioners can do anything to save lives can be tempered, it seems, with certain vigilance shown by the parents. While they know they and their baby have to be there, they watch the nurses and other staff closely, protectively, searching for clues that their trust is warranted. Jamie McDonald describes the reality of parenting in the NICU: *But we spent a lot of time sitting there, and unfortunately, it's not like you're keeping track of the nurse, but you observe because you're there fourteen hours a day, watching...*

Searching for Clues of Competence and Care

Above, Jamie refers to knowing a nurse is capable, and that knowledge allows her to go home at night. Trust can be conceived of as having two precursors: understanding that the person you are trusting is competent to do what they say that they will do and that they honestly possess the intent to do what they say they will do (Govier, 1998). The participants of this study do not describe consciously seeking out such 'proof' that they can trust practitioners. As the parents admit, they would not know what to look for at the beginning. Rather, as Jamie McDonald expresses, it is by virtue of being there, of *watching* nurses care for their baby that they learn what neonatal care consists of and consequently react to the manner of the practitioner providing that care. Shannon

Wright felt the competence of one nurse was confirmed after noticing that other nurses treated her as an expert,

> *I guess another thing that helped, that made us have faith in her, is that all the other nurses were asking for her help "Can you do this for me? Can you come help me here for a second?" Oh yeah, everybody* [asked her for help]. *Something needed to be done, she was helping.*

Eva Carter noted that even if the nurse looking after her baby was not an expert, she continued to trust her if they sought help to answer questions.

> *if they didn't know the answer, they would check with another nurse, or check with the charge nurse or a doctor or something like that. And that's what kind of made me feel a little more...reassured.*

Trusting the nurse to provide competent, well-intentioned care does not necessarily mean the parent and nurse get along well themselves. Maja Delich explains

> *Well there were nurses that I didn't like personally, not that I didn't like, but I didn't have this urge to talk to them but they were great with him. So I respected them, you know? Not many, but I remember one nurse that just really was annoying to me, but she was great with him. She was even nice, even warm. I liked to look at her when she was around him.*

Jamie McDonald recalls her husband's reminder that the nurse's care of their baby was most important:

> *I wouldn't necessarily like the personality of a nurse, and he would clarify for me, "Jamie, it's not a matter of how you and the nurse get along, but how he or she cares for Ali." He kind of opened my eyes with that because it really didn't matter to me if the nurse and I* [got along].

She considers this as she says it and modifies her remark somewhat - *I mean, it did and it didn't.* She reflects on being able to appreciate and trust a nurse's care without necessarily achieving a relationship of their own:

> *You just meet her and you think, 'Oh my goodness, she has no time for me,' but oh, how wonderful she was with Kate. And so...we didn't have*

> *to get to know each other a bit, but she was just well, capable. Capable people, kind of treated us the best, the way we liked.*

Finding Clues in the Little Things.

As their time in the NICU progresses, the parent participants in this study refer to trust as something that can be *built* and *proven.* Conversely, health practitioners can prove themselves to be untrustworthy and the trust is shaken, to a large or small degree. Evidence of a staff member's good intent while caring for these babies in general was observed mostly in small details. Jamie McDonald says that, *these tiny little things that we saw over the course of being there build trust, for me anyways.* For example, she refers to walking in and seeing a nurse taking time to soothe her baby:

> *You'd know that this nurse was going to go above and beyond, do whatever it takes to make her settled. And all of a sudden, like, sometimes it completes it. You just trust that this nurse is going to make her comfortable.*

Ivan Delich is moved when he sees nurses who

> *talk to the child when they open that isolette, they talk to them...*[they say] *how you doing and all that, have a little chitchat with the child... I think it just sort of creates a bond right away and I start liking the person.*

Kate Myers describes these little things also facilitating a relationship of trust between the baby and nurse directly, and her appreciation of this from the nurse was a secondary sort of trust:

> *and just even the little things, she would always put* [Julia] *on her tummy and put a big washcloth folded up underneath her chest so that she was kind of curled around it . . . and she just loved it. And every time she* [the nurse] *did it, she* [baby] *would just,* [making sighing noise]*...And so you could just tell that she* [the baby] *trusted her too...they built a little trust.*

As parents, we can be so deeply invested in the experiences of our children that they have more meaning for us than if we ourselves had the same experience. It seems here that Kate Myers recognized this nurse as authentically being with her baby, not to appease Kate, as her mother in any way, but rather because she saw the baby as a person in her care. Kate Myers was able to differentiate between the baby trusting her nurse and trust between herself and the nurse.

Of course, as trust can be built on "the little things", so too can a case for distrust, through the similar actions of observing the manner and nature of the nurse's care. John McDonald explains

> *The trust that you have in any given situation, I think is built based on past experiences too. So, you have the one bad experience with the nurse, I mean, nothing against her personally but you know how when you're talking to someone, and they're just not there? Or you're watching someone do something and their mind's somewhere else?*

Eva Carter remembers sitting at her baby's bedside one day and noticing that the nurse had mixed up her baby's breast milk with another's and was about to start tube feeding the other baby her milk. The feed had not yet started, and Eva remembers alerting the nurse who was very apologetic. Although Eva recognized harm was not likely to occur because of this mistake and does not describe herself as being more than mildly upset, she becomes more vigilant. *I was just, every time I went in, I checked the label on everything, although I still had no idea whether that label was actually what was inside, but you have to put some kind of faith.* She acknowledges that there are limits to what she can make sure of, however; perhaps it is enough for parents to feel like they are doing "their share" of ensuring competent care, whether or not they could trust the staff to follow up on it. Kate Myers made use of dry erase boards placed by the bedsides for parents and nurses to write notes about the baby's preferences and goals. She says

> *it was nice because it was right there if any new nurses coming on who didn't know her they could look at that, and I don't know how much it was done, like how much the nurses really did look at it for . . . But it was more helpful for us, it was like, you know, if we're not here, at least there's our input, and it was right there.*

Jamie McDonald describes her conclusion that her family perceived different 'levels' of trust in the NICU. *So medical decisions we trusted, individual nurses we trusted, but the communication through the channels of administration, we were not always confident that* [what we asked for] *was going to happen.* They describe that there is a sense of general trust, that this is the right place to be and the right decisions will be made regarding the babies' medical treatment. There is trust towards individual nurses, until something happens to call the trust into question. But the trust breaks down most often on a system level, making it difficult to trust that expected communication will happen, or that what a parent wishes for their baby will be respected when they are not there.

Trusting and Being Trusted

As the parents get to know their babies over the course of a lengthy hospital stay, it is important to them that this knowledge is respected and trusted by the nurses. One mother's experience reveals some of the complex and nuanced elements of trust that can be experienced in the NICU. Kate Myers begins to tell me about her experience by prefacing that her baby, Julia, was *quite active* and she perceived the NICU staff to prefer the babies to be quite 'sedated'. She became concerned when a nurse gave Julia a dose of Chloral Hydrate (medication to help the babies sleep), followed 30 minutes later by a dose of Morphine; the baby went on to experience more frequent periods of bradycardia (heart rate slowing) over that shift and the following day. Observing this made Kate feel

> *quite angry* and *so frustrating to me. And I just wished that she had talked to me. And the next day, another nurse was on, and she had said, 'Well, she's sick, that's why she's brad-ing* [having bradycardia] *like this, and she's sick.' And I said, 'No, she's not. She's not sick, she's over-sedated and that's it.'*

Kate did not feel trusted by the nurse who gave her daughter the sedatives, nor by the nurse the next shift. She wondered why the nurses would not listen to her and was frustrated when she felt the nurses did not believe her. When her knowledge of Julia was not acknowledged, it caused Kate to doubt her ability as a mother: *You think that you're stupid, that you know nothing about your baby.* She perceived the nurse as not being open to any input from her as Julia's mother and described her as being *quite put off by the fact that I was saying 'no she's fine.' And we kind of butted heads about that a little bit.* That evening was uncomfortable; Kate describes the tension between herself and the nurse who had given the sedation as so thick *you could cut it with a knife*. Kate is a nurse, and although she did not have professional experience looking after neonates, the double sedation bothered her and she explicitly questioned the nurse about this practice. She was angry because she could see the nurse's decision affecting her baby's well-being, as she experienced more frequent episodes of bradycardia, increasing her risk of having to undergo a series of invasive tests. The nurse's actions caused Kate to doubt her judgement in general and it became difficult to feel that Julia was safe. Kate felt that she was too angry to deal with the issue any further at that time.

> *So I just planned to deal with it later. But I made it known that it wasn't okay with me...and I stayed there. I really didn't trust this girl; I didn't really trust her decisions. And she was working the night shift. So it was really hard for me, but I stayed there until 1 o'clock in the morning until she kind of came out of the station, and watched her, and then went to bed, and then I phoned a couple of times in the night.*

The next day, the nurse practitioner sought Kate out because of the bedside nurse's concerns. She asked Kate

> "*Well, what do you think? Should we do a septic workup?" Which is the whole shmeil* [several different laboratory tests including blood, urine and spinal fluid analysis]*... And I said, "No she's fine, she's not sick, she's just over-sedated." And so the nurse practitioner said, "Okay, we'll see how she does, we'll see how she is tonight, and we'll see." And that night she came up to me and said, "You made the right decision. She's fine."*

The nurse practitioner listened to Kate's concerns and trusted her opinion about what was happening with her baby. Govier (1998) suggests why this experience was so important to Kate: "When people need to trust us, they want some sign that we care about them as people and are not prepared to harm, exploit, or manipulate them" (p. 209). Wishing to be seen as people is the concluding theme in this research.

Coming Face to Face: Please See Me

Holding My Baby: Moments of Being Seen

What follows are the descriptions of two mothers holding their baby for the first time in the NICU. Both of these mothers, Maja Delich and Eva Carter, are very satisfied and appreciative of the way their respective nurses approached helping them to hold their baby, yet the approaches are very different. Maja Delich remembers sitting by the bedside of her baby, four days after he was born, watching. His nurse that day asked her if she had held him yet. Maya responds saying that she did not know she could hold him. She has been worried that he was not stable enough, and she did not know how to hold him. The nurse responds by saying "*Oh, of course you can.*" Later in the day, she asked the nurse when the best time would be for her to hold Nicholas. The nurse responds by saying *"You can hold him anytime you want to."* Maja replied *"Oh yes, I want to right now!"* She describes how thrilled she is to be holding Nicholas, finally involved with him as a mother should be.

> *Oh, I remember this moment. It was just when she put him on here* [points to her chest] [illegible] *was shaking. He was shaking because I was. It was total, I don't know if I have ever felt that way. I thought I was going to explode from emotion...I felt so important, like four days after he was born, I felt oh, there is something that I can do.*

Maja deeply appreciated the nurse's attitude about holding the baby, being very supportive but allowing Maja to be ready in her own space and time. She describes the nurse: *she was kind of so thoughtful, you know not pushing, she gave me time to prepare. I felt like she was in* [me]*...feeling everything I feel and* *knowing what I think.* The manner of this nurse affected Maja profoundly; moving her to experience herself as mother.

> *Because it was like I* [was] *still lost in that space over there and so – it was an incredible feeling when I first held him and... I just clicked something, I felt comfortable to hold him, I felt comfortable to touch him, I, she was really, telling me do this, do that. So, if she tells me to go and change his diaper you know I am sure that I can do that without hurting him.*

By allowing Maja to come to terms with holding Nicholas gradually and gently, this nurse helped open her up to being able to move from mother-observer to mother-enactor. From Maja's story, it might be easy to conclude that the 'right' way to help a mother hold her baby in the NICU is to give the mother plenty of time and space.

Eva Carter had not held her baby yet when he was three weeks old. One day, while visiting at the bedside, she describes the nurse saying *something about holding him.* Eva responds by expressing her longing to hold him *some day*, believing that Aaron had to be off the ventilator before she could hold him. It became clear to the nurse that Eva had not yet held her baby. She asked Eva saying bluntly *seriously, you've never held him? I can't believe you haven't held him yet, well we'll have to do something about that.* She reassures Eva about being able to hold Aaron while on a ventilator and *rushed off and she came back with a respiratory therapist. She got me one of the rocking chairs and* [said] *sit down and make yourself comfy* [because] *you're probably going to be sitting here for a while,* suggesting Eva could hold Nicholas as long as she wanted to. *And that just completely made my day...because I wasn't expecting it; I just went in there for my nightly visit kind of thing.* Eva thinks that if the nurse had asked her if she would like to hold her baby that she might have hesitated, thinking that he was not ready and not wanting to place him in harm in anyway.

> *But she really took charge and it, I don't know, I found it very nice. Someone else's perception might have been that she was too forceful and*

> *all this kind of stuff. But to me it was just like oh wow, thank you. And, I don't know, I still remember that.*

These two stories show us how, in a caring relation, it is not always possible to know what to do ahead of time. These two mothers have already missed out on being able to hold their baby immediately after birth; the first 'cuddle' in the NICU takes on deep meaning related to being a parent, because parents hold their babies. NICU nurses and others need to support this developmental moment and recognize its importance (and I think do). However, reflecting on these two moments as described by NICU mothers helps us to realize that the question that practitioners need ask is not, 'do I allow the parent time to adjust or simply start making the arrangements necessary for the parent to hold', but rather, 'how can I be with the mother in a way that I see what is necessary for her, on this day and at this moment?' This may begin with acknowledging that asking this question and being open to remaining uncertain of any absolutely correct action, is ethically important.

Do You Know My Name?

Eva Carter appreciates the significance of being *acknowledged as a person other than a mom* and refers to a nurse who *would actually ask me, oh what did you do this weekend, or if she noticed that I was reading a book, she'd ask me about the book or have you read this?* She felt recognized as a person who *still* [has] *other interests and stuff like that, and so it was just kind of nice that some of them would take the time to discuss other things with me.* To Eva, being acknowledged as a person or not by the nurses was reflected in what they called her.

> *It's something that's kind of bothered me the whole time through; the majority of them wouldn't actually call me by my first name. Even though it was written on the kardex, it was written on everything, it was written on all the stupid little forms and they couldn't bother to look and see Eva. They would call me 'the mum'. And, I can understand why they do that...but at the same time, I am a real person and it just, it made me feel,*

> *well I felt a little better when there was a connection when they called you by your first name instead of 'mum'.*

These words of Eva's prompt us to ask: what does it mean to be named?[6] Can our names, most often given to us by our parents at birth, come to be synonymous with our identities? I am Gillian. By identifying myself by name, I have described myself in a whole, complete way. Our names describe us inclusively and, also, as being full of potential. As our identities and accomplishments, even our worldviews change and develop, our names have room to hold all of these things. When I was twenty-one, 'I am Gillian', referred to me as I was then, a student, daughter, friend, feminist, nurse, etc. Now, 'I am Gillian' refers to the person I have grown into, all of the things I was at twenty-one plus many more; mother, wife, nurse consultant, graduate student, writer, qualitative researcher, and more. After the birth of one's first child, being called Mum, Mama, Mother by your partner, friends and family is thrilling to hear: it is novel and affirming. When that child himself calls out these names, as perhaps his first or second word, mother and child have reached a sweet milestone in their lives. Becoming a mother seems to happen through the experience of being one, and being called Mother contributes to moving you there. But can being called Mum, or "the Mum" as a generic label, instead of your given name limit the possibilities of the Woman, even if only for that moment?

Maja Delich describes a transitional moment when a nurse whom she had originally felt "annoyed by" made a decision related to the care of Nicholas that deeply touched her and her husband. Maja describes categorizing a particular nurse as a "policy-follower" because she requested that the parents not turn off the monitor alarms for their baby, although other nurses had let them do this. (Heart and oxygen saturation monitor alarms are sensitive to movement and frequently sound with false positive indicators, although it is considered good nursing practice to always assess the reason for the alarm.) At one stage, when Nicholas was very ill, he required Pavulon, a neuromuscular blocking agent used to facilitate mechanical ventilation that effectively "paralyzes" an infant, making them incapable of any voluntary muscle movement. It is given intravenously every 60-90 minutes to maintain a steady state of no movement. Seeing their baby on Pavulon can be very disconcerting for parents, even as they know it is contributing to the best treatment for their baby.

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[6] I would like to acknowledge Dr. Vangie Bergum for asking me this question during a discussion about my research.

> *But also, and I loved that nurse, she's amazing, when Nicholas was very sick, she was supposed to give him Pavulon, but because we were always holding his hand, one him* [Ivan] *and I was on the other side and he was sat-ing* [Oxygen saturation] *high, it was like a moment when he was doing really well and she was holding the Pavulon for more than an hour, more than she was supposed to, just to prolong the moment. That was oh, something. I said thank you, just as she was leaving the shift, I hugged her and said thank you because I knew that she knows.* [voice breaking] *Yes, she was still a human more than a robot.*

What is Maja referring to - what does the nurse know? Does she know what an impact that feeling even the tiniest wiggle of your own very ill baby's fingers can have on a parent? Can she know what it means for parents to understand that the baby has become stable enough to even consider holding the medication a few moments longer? This nurse assessed not only the baby's physical condition, the numbers on the monitor and his lab results. She saw in front of her what must have looked a sad but beautiful family portrait; quiet and tired parents flanking an impossibly small and, aside from the regular, mechanical chest movement, perfectly still child, their first and only one. She responded to this image before her in the way that she could. It may be that when Maja says that the nurse is still a human, she means that to the nurse, she, her husband and their baby are also still human.

Jamie McDonald remembers a brief moment that has stayed strongly with her since being in the NICU. It happened while Ali was being prepared to be transferred to another site for surgery. Jamie says

> *we wanted to be there but we didn't want be in the way. So, I was kind of off in another spot, where there was a newbie* [new admission] *spot set*

> *up or something, and I was a little teary and I was a little nervous and the neonatologist actually came to me and asked me if there was anything he could tell me or do, he* [asked me] *are you okay? Do you need more information?*

This exchange seems reasonably simple and when I asked what had made this moment so memorable for her, she replied

> *well just the fact that to the neonatologist, we weren't just another baby in the row. He actually saw us as, I don't know, concerned parents that needed some reassurance. He actually came, he approached us not just to talk to us about our baby, it was like, what information can I provide you that will make you feel better to move to the Stollery?* [To have the surgery] *Like, that's just a little tiny fraction of a second kind of thing but it was like, ok, I'm a real person to this doctor.*

In just 'a little tiny fraction of a second', this physician made an indelible mark on Jamie and John McDonald's memories. This moment of responding to their worry by recognizing their distress and offering to help became an ardent and enduring memory of being seen as a person. In that short moment, the physician and parents shared a moment of common humanity.

Christine Hayes describes a similarly small but potent moment of engagement. Following the birth of her twins she needed to recover physically from a Caesarean section and was unable to come to the unit to see the babies until a day and a half later. She describes her state of mind:

> *I was very emotional at that point, hormones for one thing, I just couldn't stop crying and knowing, that you just didn't know whether they were going to survive and then it's intimidating walking in there for the first time*...The nurse looking after her baby *was so compassionate, and she said you can touch her hand and so I had touched her hand and right at that point I started to hyperventilate and of course I had a c-section, I couldn't breathe, I was in so much pain, oh my goodness.*

What resonated with Christine about this encounter was

> *how she cared, it wasn't just at that point that this was a job to her and she really, she hadn't experienced a baby herself, but she could see the pain that I was in at that moment...She just, she grabbed me and she put her arm around me and she said it's going to be okay, and there was almost a tear in her eye, like you could just see that she was sincere in how she felt for me at that moment.*

Christine describes this nurse as one of the most memorable in the unit even though

> *as my stay there went on we'd run into each other in the hall and she would stop and talk to me and say how are you doing and how are the babies. She would come and see the babies. I think she was maybe only, I don't even know if she was ever on the babies after that again, maybe one other time in that three month time.*

This connection between Christine and her nurse that day did not take a lot of time to develop, similar to Jamie McDonald's description with the physician above. Rather, the connection is forged by the power that happens when coming face to face with someone and having them respond to your call.

Primary Nursing: Will You Be Our Nurse?

I felt like she was feeling everything I feel and knowing what I think. This is how Maja Delich describes feeling about Nicholas' primary care nurse after the nurse helped her to hold him for the first time. "Primary nursing", in this context refers to a commitment on the part of a nurse to care for the same baby on her shifts over his entire length of stay, thereby getting to know the baby and parents well. It involves, as well, actively participating in an overall, comprehensive nursing plan of care that can be referred to when she is not there. Maja refers to being able to

> *tell her anything, I could joke with her, I was close to her and if she was doing something, I could even* [ask] *her how come you're doing that? She wouldn't get me wrong at all, we were so personal, you know. We clicked together.*

What does it mean to "click" with the nurse looking after your baby?

Kate Myers describes how Julia's primary nurse, Sue, entered into a relationship with her. It included foremost being comforted by her care of Julia and by the way she spoke to them about the situation.

> *This nurse, she just came to our level, she came and she said, You know, I don't have any idea how you feel, and I will tell you that right out, I have no idea what you're feeling and what you're going through, but this is what to expect.*

During those early days, Kate and her husband also began to get to know Sue, and she them.

> *in the first couple of days we didn't only talk about the baby...she would tell us about her fiancé, about their plans, and about where she was from, and we would talk about all that stuff...and it was like we connected on a personal level as well as the common – the commonality was Julia, of course.*

Perhaps because they got to know each other so well, Sue understood what Kate needed as a mother in the NICU, when on one occasion Julia required a blood transfusion in the middle of the night. *And she phoned me at 2 o'clock in the morning and she said, "Listen, just so you're not alarmed, when you come in the morning, we are giving her another transfusion".* Kate deeply appreciated, not just the information, but the fact that Sue knew to make the call late at night. Calls to parents in the middle of the night are generally reserved for emergency situations, but this nurse knew that Kate would want to know what was happening with her baby, even if it meant being woken up. Kate wanted to be fully involved in her baby's care and life. *I don't care – you can phone at 2 o'clock in the morning – I do not care. Phone me if she's fussy and she wants to be held – I'll be there.* This kind of communication between Kate, her husband and Sue make possible a relationship where the parents are able to be relieved by what she tells them. That is, not reassured that everything will be all right, but that they will (all) be able to handle whatever comes their way during Julia's course in the NICU. When they are worried about a potentially serious problem with Julia, Kate describes how Sue spoke with them about it: *she would just say,* *"Don't worry," and that was enough. We'd* [think], *okay, we don't need to worry about this, it's okay, we'll just deal with it.* We can almost hear the nurse's subtext: whatever happens, I will be here with you.

Not all of the parents who participated in this study had a primary nurse. Shannon, whose baby was in the NICU for two weeks, did not mention primary nursing. However, she and her husband believe that the reason their daughter had an unexpectedly uncomplicated course (compared to what the physicians had told them to expect) was because she had the same nurse for four consecutive shifts after her surgery and that this *started her off* in such a positive way that it influenced her whole course of care. The other families, who were in the unit for a lengthy admission but did not have a primary nurse, all spoke of wanting to have one and of not being sure how they might have navigated the system differently to get one. Eva Carter's baby was in the NICU for over five months. Already several weeks into her experience, a nurse makes a comment to her assuming she has a primary team. When Eva responds questioningly, the nurse is surprised that her baby has not had a primary nurse, but explains the concept and tells Eva that she will organize a 'request' for a primary team on Eva's behalf.

> *I don't know whether no one signed up for his primary care team or whether she completely forgot and never put up the thing because there was nothing ever done about it again. So that was something that really kind of bothered me in general about the whole thing is they have this thing that studies have shown that babies within primary care, were seen everyday, that kind of thing, tend to do better, so why don't they do it?*

She is bothered that nothing ever comes of her primary team, although she understands that the nurse might have forgotten. *And so every time I saw her after that, I would just wonder did she forget? I can understand forgetting, getting busy, we're all human, but I would kind of think, did she forget?* Eva seems to be hoping, in some sense that the nurse did forget, because the alternative explanation is clearly much less palatable: *Did nobody want to be on my primary care team? Cause I was so emotional? I don't know.*

John and Jamie McDonald similarly do not get much response from a unit generated request for a primary nurse. When they start to inquire as to why no one responds, they learn that nurses are afraid to be rejected themselves.

> *We talked to them about why is the response so low and I mean why is no one interested in this when it makes so much sense and that was the comments that we got - they don't volunteer because they're worried about being rejected or not being what the parent is expecting* (John).

John finds this hard to understand and wonders if it is something else, something about the behaviours of the parents that turn some nurses away: *oh, those two ask way too many questions and I don't have that kind of time. You know what I mean? Maybe it's not a rejection of the kid; it's a rejection of the parents.* What might parents think is being rejected? And, how might their experience in the NICU change, if every time they come in, they wonder about being good enough, or easy enough to get along with or too demanding for the nurses to choose them? Jamie and John continue to initiate a primary team by directly inviting individual nurses to consider being a primary nurse for their baby. Initially, they experience *difficulty in getting people to be interested in it.* They wonder if it is the shift length and eventually some nurses who work the shorter 8-hour shifts do sign up: *Then after that, we had 5 or 6 people signed up and it was frustrating because they'd come to work that day and they wouldn't be assigned to Ali.* Kate Myers also experienced asking a nurse directly to be on Julia's primary team and the nurse refused, explaining,

> *because I had an experience where I got really, really close to this little boy, and I was there and, worked full time, and was there all the time with him, and then he just left, and it was heartbreaking, because that was what I was used to, being with him every single day...It was just heartbreaking. I don't think I could do that again.*

It would be interesting to further explore these feelings with the nurse since it is difficult to understand how the baby 'just leaving', when discharge always remains the ultimate goal of care in the NICU, was so devastating. What happened here that we do not understand? Kate wonders if there is something, [illegible]me *stigma or something, like maybe something bad happened,* to cause [illegible]ary nursing to be interesting to so few nurses.

Christine Hayes does not express the same frustration or disappointment about no one answering her request for a primary team. From her experience, it was common to not have a primary team and she accepted that as normal. *Actually there were quite a few mums that, the ones that were going to be there for a long time, had applied for it. But very rarely did anyone really sign up.* Again, she understands: *I think it would be fairly difficult to sign up all the time, just because of boredom in a sense.* However, she also recognized benefits for the nurses. *I think there would be a positive thing about it as well; knowing the baby, because often you would have a* [different] *nurse come on and they'd be asking me all about the baby.* Even though she is resigned about not having a primary team, she much preferred when her babies were cared for by a nurse who knew them well.

> *I found those relationships, the ones that you would see a nurse more than once or twice, they were refreshing. It was like oh good; it's someone that kind of knows what you're about and knows your baby a little bit. I always enjoyed those nurses who were on for more than one or two shifts.*

Walking in the Nurses' Shoes

The parents expressed deep respect and understanding of the NICU practitioners' experience in caring for the babies and parents of the unit. For example, Maja Delich explains how she was always trying to imagine what the NICU was like from the perspective of the nurses: trying to put herself into the "nurses' shoes". She remembers a day when she and her husband had been dismayed by a nurse who did not seem to be attending to their baby, but rather just recording the numbers on the monitors. Ivan, in particular, was worried and angry about her care of Nicholas. Maja reflects on what it might be like for a nurse walking up to the bedside of an ill child.

> [I tried] *to see how if you see the two of us worried, sitting around him with faces "don't come close to me"; it was total—I don't know what I*

> *would do if I were in her shoes. So, that's why after when I think about everything I understand totally why she was like that and you know we were so mad. We were mad at the situation, what's happening in our life and she was there and it's easy to blame...*

Jamie McDonald, although frustrated with not being able to set up a primary nursing team, still makes allowances for why the primary nurses do not receive her baby in their assignment.

> *So staffing wouldn't necessarily implement the primary care team that was in place, however, we know staffing probably has a million different things to deal with and a primary care team would be at the bottom of the list.*

While remaining appreciative of her understanding the competing priorities of the unit, we must ask, why would she assume a primary care assignment to be at the bottom of the list? Why would she think that thoughtful patient care and nurse preference (these nurses had, after all, requested to be assigned to her baby) rate low: what has caused her to think this?

Parents can struggle with their expectations of care for their babies and themselves. Although they express wanting to see the baby receive good care as most important, they acknowledge that they are provided care as well, and they are grateful for it. Ivan and Maja Delich discuss what is appropriate to expect from a nurse in a busy NICU. Ivan is discussing watching a nurse taking care of Nicholas one day.

> *Exactly, doing her job, doing her job and I completely understand – now why should she come and chit-chat with me? Like there's no real reason for that. She comes here to do her job and I'm the parent of the child that she's taking care of and that's it. I think the care of the baby* [should be the] *primary goal and then parents are sort of a secondary thing there.*

Maja is thoughtful as she replies, reflecting on how this territory of caring for baby and parent is negotiated and enacted in the NICU. *They also care about parents, I think in the NICU.* Ivan immediately agrees *Yes I can see that definitely there,* and, on reflection, it seems he might be talking in terms of priority setting, of triage in a sense. What he means is that he will ask his questions at an appropriate time, not wanting to interrupt the nurse while she looks after his child, and not that he thinks he should not ask the questions.

These parents have expressed empathy and understanding of the nurse's role in the NICU. They remain, however deeply connected to their children and realize, particularly in retrospect how the condition of their baby influences how they see the nurse, and judge her care. Parents are deeply influenced by our children, their moods, their experiences, and their well-being. So it is in the NICU. Maja Delich explains realizing much later that Nicholas' illness coloured her impression of a nurse: *Afterwards, we got very close with her, you know. At the beginning, you know, I didn't like her. She came and she seemed to me too cold. But it's just because Nicholas was very sick at that time.* Her husband, Ivan, also remarks on the way in which their sick child influenced his whole world. When Nicholas was unstable and ill, he found it very difficult to see beyond the baby, even to the world of the nurse.

> *Maybe she was doing the right thing. At that point, when your kid's sick, you don't really act like everything's okay, objectively. You just look at him, that's what you do. And, you see something and if that nurse is not there right at that second* [you are upset].

The parents are made both vulnerable and strong by their love for their baby. Jamie McDonald describes similarly, how simple and absolute the connection is between her state of mind and her baby's well-being. S*o, I'm at the hospital, I'm already having a bad day because Ali is having a bad day.* In her expression, we can see that what she is saying here is "I am worried", but also Ali does not feel well and Jamie seems to feel this as if she, too, is unwell in her own body. This connection to the babies' bodies is further shown when the parents reveal that the way the nurses touch the babies influences their perception of the nurse. Christine Hayes describes the nurses she would feel uncomfortable with:

> *I think they were so comfortable with how they handled babies and when you're handling babies you tend to maybe be a little bit more aggressive and I'm not saying that that's necessarily a bad thing, but when you're a*

> *parent and a new mum… I, there were times, that I wouldn't have probably handled my babies, my newborn babies that were full term as aggressively as they* [her premature twins] *were sometimes being handled.*

Eva Carter similarly describes feeling more confident in the nurses who handled her babies gently.

> *There was one nurse that, well he was intubated and you know how they flip their body? And then they'd flip their heads afterwards? Well she'd like flip his body and then flip* [demonstrates quick hand movement] *his head and I was just like ohhhh, you're going to snap his neck there. She* [said], *oh no, they're fine and I* [said] *okay.*

Eva sounds very doubtful about the nurse's reassurance as she relates this story. As forgiving and understanding of the nurses as the participants in this study were, and as likely competent and confident as these nurses were in their handling of the babies, are we expecting too much? Is it simply to much to ask parents of babies to see us, practitioners, handle their babies in ways they deem rough and aggressive, even neck-breaking?

Just Another Parent: Moments of Not Being Seen

Kate Myers describes a day when her daughter Julia was doing very well and seemed to need less assistance from the ventilator. Kate, her husband and the bedside nurse suggest that the breathing tube be removed, and the baby's breathing be supported by a less invasive method instead. Kate mentions this to another nurse on the unit who responds to them by saying *Oh, well, she won't last for more than a day* [without needing the ventilator again]. Kate is taken aback, angry, hurt, and wonders *I mean, so . . . you just* [want to say] *Excuse me? Why are you being so negative?* She goes on to explain that the reason this sort of comment is so destructive is because

> *that's all you live* [on] *in there, is hopes – hopes and wishes and dreams, and that's what you live through and that's what you live on – like, well I hope that she gets to go home before this time; I hope that she will be extubated; I hope that everything goes well. That's what you live on. And*

> *so it just felt like she was crushing everything that we had hoped for. And so when she did only last three hours, she* [the nurse] *had come back and actually said, "Well, I told you." And that was so frustrating, because we just felt like strangling her and saying, you're not helping anything. We were already devastated that she only lasted three hours. Yeah we do realize it happens all the time, but it doesn't matter. Even if it does happen all the time, it's never happened all the time to us.*

Although the nurse may feel she was 'proven right', what does that mean to Kate and her husband? What would have been different if the nurse had chosen to express her expectations with hope? What if she had remarked on how much improvement it was for the baby to come to the point where extubation was given a try? And, afterwards, what if she had commiserated with them and reminded them how well Julia had done to have the tube removed even a short while, that every attempt comes closer to being extubated for good?

Christine Hayes expresses how one negative incident affected her, during three months of otherwise feeling *very comfortable with who was there and how things were*. Christine lived out of the city and tended to stay in Edmonton to be with her twin babies for several days at a time before returning to her family for a few days. She describes one evening when her twin babies had recovered enough for her to bathe them and feed them and do much of their bedtime care. She came in with such regularity that the nurse looking after her babies expected her. On this particular night she had not intended to come in as early as she usually did when intending to bathe them. When she realized that the nurse had expected her to be in and do the baths, she started to prepare one baby for the bath and the other one started to cry. At the same time her husband, who she had not spoken to for two days, called to inquire about the babies. It is hectic, as she describes:

> *so I was talking to him and I had asked the nurse could you please finish this up because he* [the baby] *was in the middle of* [being prepared for his bath]. *I suppose I could've asked him to call back, but she said okay, and I talked for about ten minutes and then hung up and she said she hadn't*

> *done anything and I didn't realize that and she said well you can finish him up. But in the meantime, Lily had been crying for ten minutes and it wasn't like her to be doing that and so I wanted to go settle her and she said, well, no you can do this. Well, I said I thought that you said that you would do it, you know? And, but the whole time this was, she was really aggressive with me, she talked to me very gruff and not very pleasant at all.*

She pays attention to what her contribution might have been to the harsh conversation:

> *And I was very sure that I was talking to her quite nicely because my husband had overheard me on the phone asking if she could you know finish her up. So, anyways, this all came to a big head and she said "You know what? They're your responsibility, you're going to be going home and you're not going to have somebody looking after your kids. You're the mom and you need to do this." And so I was obviously put off. I was pretty upset. I felt like I didn't need to be talked to that way. She said "oh and if you can talk on the phone you can finish your baby" and, well, right then and there I started bawling my head off and I had said I hadn't talked to my husband in a couple days, he was phoning to see how they were doing.*

The challenge to her self-as-mother does not go unnoticed as she relates the story to me: *And, I know that I'm going to be responsible for them but I also thought this was part of her job as well, I was there to help but I wasn't the primary caregiver.* By this time Christine *was shaking so hard and crying so hard that I couldn't even do anything with the baby at that point.* I asked her how the nurse responded to her crying. Christine's reaction is bleak: *Nothing. Not a single thing, she just left and finally I said "Could you please just go away?" cause she was sort of in the, it's a small space, but, I was just so upset.* Eventually the nurse suggested she get her assignment changed to which Christine agreed. Although this is the *only bad experience* she had, the lingering frustration and hurt is evident in her voice during our telephone interview.

The Prognosis Talk: I Need You to Know

Many of the parents referred to the difficult discussions they had with physicians about the prognosis of their baby. These talks usually happened while they were in premature labour and were often structured around statistical likelihoods of survival and disability outcomes of babies born so early. Christine Hayes remembers the neonatologist coming to her room in the antenatal unit:

> *They would come and tell you, and they're very straightforward, okay if your baby is born now, because I went in at 24 weeks, this is what is going to happen if they were born, and basically the survival rate was very, very low... they really don't give you a lot of positive information. They don't want to get your hopes up, and there wasn't ever a time where they said, okay, this is good.*

Ivan Delich similarly remembers being told about outcomes at the very beginning and describes it as being very hard to hear; he says hearing the truth sounded *naked and so brutal.* They say *maybe your son will never go to college, he will never get out of bed*...as *a parent it's killing me. I still think he's going to be the best.* At the same time, Ivan believes these discussions are *very necessary to hear. To face it at the point where you're supposed to be facing it*...Ivan believes it is necessary for every parent to hear these possibilities so that they can be prepared for the worst outcome. He states he would not like to be told *don't worry, don't worry and the next moment something goes bad and I'm not prepared for it.* Eva Carter agrees: *I know why they tell you all those things, just in case it happens then you can be partially prepared for it.* Then, she says, reflectively, *not that you can really prepare...*

Kate Myers describes the talk with the neonatologist as *black and white, just the nitty-gritty* before she gave birth to Julia at 24 weeks gestation. The physicians asked her repeatedly about her wishes regarding full resuscitation and she describes recognizing now that she was in denial and that, as they asked her these questions, she was thinking *it'll just go away; the labour will just stop and it'll go away and everything will be okay* . Then, after Julia's birth but before Kate had seen her in the NICU, the neonatologist came to see her, explaining that they just had to wait and see how the baby would do. *His exact words were, "If she doesn't do anything stupid in the next week, we'll be all right." So, I was thinking what does that mean?* Kate recalls feeling confused about what this meant and that these words were *just kind of shocking, what do you mean stupid? What could she do that would* [be stupid]? There are two concerning aspects about what the physician said to Kate. First, referring to the actions of someone's child as stupid is always a risky endeavour. It is akin to name-calling and in most cases would be very difficult for a parent to interpret constructively. In a health care setting like this, it deeply lacks respect. Even if we allow that he likely did not actually mean the baby could be stupid, it seems too much to expect that Kate is in any state to give the benefit of the doubt. Second, and more seriously, the physician ascribes motive to Kate's tiny new daughter, as if she could in fact do anything on purpose, she might choose to do something stupid. So, while we can understand through context that he is referring to a turn for the worse in Julia's condition, let us remember that Kate had just newly given birth. She was in the midst of coping with the physical realities of that as well as becoming a mother to a critically ill, very premature baby and her physician is not being clear about what might happen. As Kate asks, what does "something stupid" refer to: dying, becoming more ill, stopping her own heart?

I have been present at many difficult discussions between parents and members of the health care team where the progress and prognosis of an ill baby are discussed and explained to a parent. I remember often entering these conversations thinking that we need them to know whatever news we were planning to give. I was not surprised to hear that these parents found the words so difficult to hear, even as they understood and supported the reason for them to occur. Still, it has made me wonder: Whose needs are we filling during these discussions? When we say 'I need you to know' what does this mean? Does this mindset prevent us from seeing them as individuals with differing needs as far as what they have to know? Do we walk into these conversations set to fill *our* need to tell? Is there a way to balance adequately informing parents so that we are being truthful with them, without seeming to give too much weight to what *we* need?

The Nature of Themes

As noted at the beginning of the chapter, presenting the themes as I have here emphasizes them as being discrete and separate from each other. While this enables us to *see* and think about them in a clear way, it is removed from the actual experience of them. In the following chapter, I reflect on and discuss the themes in a way that attempts to explore more deeply their contextual nature.

CHAPTER FIVE

Reflections and Conclusions

Having a baby in the NICU is a life-changing event. This radical departure from what is known and expected about having a child deeply influences how one becomes a parent to the baby who lives his first weeks or months in a critical care unit. The parents in this study have described how their relationships with the healthcare practitioners in the NICU shape this moment in their life. The purpose of this study was twofold: first, to better understand the moral relevance of relationships between parents of intensively ill babies and their health care providers; and second, to further explore relational ethics as a way of becoming aware and responsive to the ethical questions and nuances of parent-provider relationships. In this chapter I will reflect on how the findings of this study have revealed and made clearer the meaning and inherently moral nature of relationships in the NICU. To help us be mindful of the interconnected nature of the themes, we might think of them as filaments in a spider's web. Each plays their own unique part in the structure of the web but are connected to and influenced by each other. The connections may look delicate but in fact be very strong. It may not be immediately obvious where the strongest connections lie, and every spider's web is unique. Movement at any one part of the web reverberates through the entire structure. Such influence is shown in the parents' experiences when loss of trust leads to feeling more vulnerable and the need to become more vigilant. The experiences represented here by themes may be enacted differently by each individual parent, as shown, for example, by the two different descriptions of the mothers' first time holding their babies.

First, attention is given to seeing the ethical nuances as they happen: moment by moment. The themes themselves will be discussed by focusing particularly on their relevance to ethical relations. The environment of the NICU is discussed as the physical and moral context for the parents' relationships with NICU practitioners: What does it mean to have aliens looking after the baby? The theme of *feeling vulnerable; becoming vigilant* provides us insight with which to explore the embodied nature of the parents' experience. I consider the complex, intricate nature of trust in the NICU, expressed by the parents as necessary to feel at ease when leaving the unit for the day. The concept of relational autonomy (Bergum & Dossetor, 2005; MacDonald, 2002) is suggested as a way to think about how parents and practitioners in the NICU can be in relation, allowing space where both parents and practitioners are recognized by each other. Primary nursing[7] (or lack thereof) will be looked at as a possibility for relational engagement (Bergum & Dossetor, 2005) in the NICU. Lastly, implications for clinical practice will be suggested, as well as further areas of research and some ending conclusions.

Moment by Moment in the NICU

At the beginning of this text, I acknowledged my interest in the 'broader moral landscape' of the NICU as the place where ethical relationships between parents and practitioners happen. Throughout this study, I have become more and more conscious of seeing 'moments' as the place where everyday moral interactions like those I have been trying to understand *as well as the more mountainous ethical dilemmas* take place. The experiences all happen moment by moment. When fully and un-self-consciously engaged in the interviews, the parents would relate their experiences by describing moments that were meaningful to them. From reading and rereading these moments of description in transcripts, the themes of the study were evoked. The word moment comes from the Old French *moment* or the Latin *momentum*, meaning movement or a particle sufficient to turn the scales (Barnhart, 1995). The parents describe many, many fond memories, but they are weighed against memories of difficult moments that seem to occur much less regularly (even rarely) but carry a weight that is incommensurate with their frequency. That is, they outweigh the positive moments because of their significance, since it is the difficult moments that may result in, for example, loss of trust, loss of confidence or the harm that is done to them when they are not seen. The difficult moments seem to have more momentum, that is, to have more *moving power* than the good moments.

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[7] My original intent with this research was to understand better the relationships parents in the NICU had with all NICU staff. To a great extent, the focus of the parents was on nurses and nursing care. This did not surprise me, as I remember from my practice sharing long hours at the bedside with parents. Therefore, portions of this discussion will seem to focus on nurses alone. This is not to suggest that staff members of other disciplines do not have important roles to play in the care of babies and parents in the NICU, nor that they should feel less obligated to engage with parents. Instead, it reflects a practical fact: nurses spend much more time touching the babies and talking to parents.

It is during moments such as those described by the parents that we can see signs of and opportunities (or missed) for ethical relation. Cameron (2004) writes of the nature and potential of ethical moments:

> When we attend to the moment, soon and gently does the next one arrive. Ethical moments begin, come to be, stand for themselves, and fade away again. Like the forming of a beautiful bubble that soon breaks, the moment encapsulating the ethical claim of the other too is short lived. Yet, what we experience and understand in that moment, we carry with us into the next moment that awaits (p.61).

I start here, considering how the ethical moments in the NICU are shaped in part by the physical nature of the unit.

What Does It Mean To Have Aliens Looking After the Baby?

As noted in the literature review, there has been much attention paid to the experience of parents in the NICU, including ways to contribute to their experience of becoming parents, while still missing explicitly an attention to the moral meaning of relationships between parents and practitioners. Captured by the theme *walking into an alien world,* the parents of this study described their first impression of the NICU as an intimidating and foreign place. Initially, their impressions are of a strange, unfamiliar place, (an alien world), which evokes fear, worry and confusion, combined with sensory overload (Brandon, Ryan & Barnes, 2007; White, 2004) and, for mothers, physical and hormonal changes. Parents often do not feel welcome; wonder if they belong and if they are a burden to staff. Consider Jamie McDonald's experience of attending rounds and facing the backs of the healthcare team. This response of parents feeling they are a burden in the NICU was recognized in a grounded theory study by Cescutti-Butler and Galvin (2003) and others (Heerman, Wilson, & Wilhelm, 2005; Wigert, Johansson, Berg & Hellstrom, 2006). The grounded theory study explored parents' perceptions of the competence of NICU staff, and the authors expected parents to link the competence of staff with tasks and skills. Instead, the "parents saw competence as a range of caring behaviour and related skills, where staff showed consideration for parents and for their baby" (Cescutti-Butler & Galvin, 2003, p.756). That is, parents saw being cared for and included in the care of their baby as integral to staff competence. This suggests that performing a task, such as inserting an intravenous line, and regarding it as separate from the person into whom the line is being inserted, is not 'competent' in the parents' interpretation of the word.

Considering the construction of knowledge needed for ethical care, Bergum (1994) suggests that subjective knowledge (signs and symptoms) and objective knowledge (science and technology) must be used in context with inherent knowledge. Inherent knowledge is "lived wholeness experienced from within rather than surveyed from without; it gives personal meaning to the events of health and illness; it includes the descriptive knowledge of personal symptoms and the abstract knowledge of scrutiny and analysis" (p.73). The discussion and decisions made that day in the rounds witnessed by Jamie were very likely excellent ones, taking the baby's symptoms and lab results into careful account. But it seems likely that even the casual observer who watched the mother being blatantly ignored would know something was deeply wrong with the manner in which these rounds were conducted. Rather than *being* a burden to staff, a burden was, in fact, placed on her as she faced negotiating a way to get into this world in order to be a mother to her child.

There is an evolutionary quality to the parents' impressions of the NICU. This has been described by other researchers as 'outsider to partner' (Heermann, Wilson & Wilhelm, 2005) and 'from alienation to familiarity' (Jackson, Ternestedt & Schollin, 2003). Parents whose babies were in the NICU for several weeks or months describe coming to regard the NICU as 'home' while always acknowledging their desire to be discharged to their real home. The feeling of being at home seems to oscillate with sometimes still feeling excluded, for example, Maja Delich's and Kate Myer's stories of being 'allowed' to perform some aspects of care with some nurses, while others would not allow them to perform the same activities. Jamie relates that as she asserted herself into rounds, she was included in them. However, every time a new physician came on service, she found she had to 'show' what kind of parent she was *again*. Other researchers similarly noted this experience of moving back and forth between feeling excluded and included (Heermann, Wilson & Wilhelm, 2005; Wigert, Johansson, Berg & Hellstrom, 2006).

Physical constructs such as light, noise, privacy, and comfort contribute significantly to the experience of parents in the NICU as reported by these participants and in the literature (White, 2004). However, as time passes, these intrusions seem to drop away as the parents become more familiar with the unit. The NICU as ethical environment also includes other, less tangible elements of space and place. These include the aspects of the parents' experience discussed here, such as vulnerability, trust, and being recognizing as a person. Relational ethics "is the creation of an environment where ethical reflection can take place" (Bergum & Dossetor, 2005, p.165) and refers, in part, to acknowledging relational space. Relational space "becomes an entity or thing in itself, not controlled by one person or the other but as a space that holds people in relation—a third entity—to which both people contribute" (p.xvii). We learn here that our choices affect those around us and their choices affect us. What if, that morning at rounds, one of the practitioners, perhaps the bedside or charge nurse, or the physician had said "hello" to Jamie McDonald, asked her how she was feeling and explained the purpose of morning rounds? What if someone had said, "Congratulations, you have a new baby, we know it is difficult to be here. We are going to go through everything, and you are welcome to tell us about your little girl, or ask any questions." How different those rounds might have been if just one person had reached out to Jamie and invited her forward. In that moment, a relational space would have been created. Instead of sending the clear message to Jamie that the practitioners were in control and 'in charge' of her baby, there would have been opportunity created for staff to learn about the baby as a person through her parent. The intention of creating an interdependent environment is to make room for difference and create opportunities for discussion and valuing all different points of view. Bergum and Dossetor (2005) suggest that relational space does not ignore or prevent issues of power, but rather, "power held in this ethical place is less sure of itself" (p.183). It may seem that the NICU is a spaceship, but the practitioners do not have to be aliens (or alienating). Entering into a relationship, creating an ethical environment with the parent facilitates the movement many parents described in this study: from regarding the NICU as foreign, to regarding it as home. The embodied experience of vulnerability may be one way into relation.

The Power of Vulnerability

In the introduction to this study, I described how the birth of my son and becoming a mother gave urgency to the clinical questions that I have addressed in this research project. The urgency was embodied through my experience of being vulnerable in a way I had never known. As a father tells his teenage son on a now-cancelled television series: "Since the minute you were born, I knew I would never take another easy breath without knowing that you were all right" (Schwartz, Heinberg & Liman, 2003). As my early postpartum thoughts returned to parents and babies that I had met and cared for in my neonatal practice, I was doing more than relating to them by virtue of a now shared experience. Rather, I *felt* the vulnerability of having a child in my bones, in my nerves and in my heart. I realized that the images coming to mind, quite unbidden, of the parents' I had known, came now because I recognized the looks on their faces. I saw that they were afraid for the life of their child. But the fear I recognized was not arising from knowledge of the chances of survival and health. Instead, this fear was the bodily acknowledgement of their vulnerability to hurt and to suffering. If I was feeling so vulnerable because of the healthy term baby safe in my arms, what was it like to feel this way and also be immediately faced with the real possibility of harm, even death, coming to your baby?

In his discussion of what it means to be vulnerable, Hoffmaster (2006) suggests that the most important part of vulnerability is

> the loss of power that vulnerability imposes and signifies, and the attendant loss of control that ensues. We fear vulnerability most immediately because of the particular harms we seek to avoid. But we fear vulnerability most profoundly because of the power we seek to retain" (p.41).

The parents in this study are immediately confronted by the particular harms they most seek to avoid, that is, any harm to their child. But, as Hoffmaster is suggesting, the most difficult aspect of vulnerability for them to face may be that, with the admission to the NICU, they lose control over their baby. The parents have no power over the circumstances of the birth of their child; they can neither stop premature births, nor the presence of congenital anomalies. Further, they perceive they are unable to help their child in any way, as Maja Delich so vividly acknowledged: *If he was left alone with me, he would die.* What she says here is simple and true. He would die if left alone with her. (Her words remind us also that at the centre of the relationships between parents and practitioners in the NICU is always the exquisitely vulnerable baby.) The parents' struggle for control is made evident in their vigilant attitude toward the care of their baby. It is made evident in John and Jamie McDonald's story of Ali's lumbar puncture as they assume the role of protecting their child; they act as parents. Even as they laugh at themselves, in retrospect, for feeling so protective and not realizing how routine and relatively safe a procedure it is in the NICU, their desperation to assert their own power to take care of their child is revealed. Lack of power and feeling out of control resonate with the parents' experience of vulnerability, as they have described it. How can the experience of vulnerability contribute to our shift to moral attention in the NICU?

Vulnerability, Hoffmaster (2006) suggests, has no place in the contemporary discussion of morality, focused on rational principles and rules, because vulnerability is felt. "It is antithetical to our emphasis on individualism and rationality; it requires that we attend to the body and to our feelings" (p.38). Turning to relational ethics, we can think again of the notion of relational space. Embodiment is integral to relationship, "relationship cannot happen without embodiment" (Bergum & Dossetor, 2005, p.137). It is from this space that we can explore the quality of our relationships (Bergum & Dossetor, 2005) and, I suggest, as shown by the parents in this research, that their experience of vulnerability can be a way *into* relationship. When Christine Hayes first saw her babies in the NICU, a day and a half after their Caesarean birth, she describes herself as teary, worried and afraid. Her babies' nurse talks to her about touching them, but when Christine starts to cry even harder and hyperventilate, exacerbating her painful abdominal incision, the nurse 'just grabbed' her by putting her arm around her and, with a tear in her own eye, told her that things were going to be okay. Could this be an example of Christine's vulnerability *compelling* this nurse to enter relationship, to create a relational space with her?

In his "meditation on vulnerability" following a clinical encounter in his practice as a clinical ethicist, Richard Zaner (2000, p.265) suggests the vulnerability of the patient (parent) is powerful in itself. The lack of power, the asymmetry of control that makes someone vulnerable, in itself, commands our attention. Zaner proposes that this "awesome vulnerability" (p.270) awakens our responsibility to the person who is vulnerable; it is the source of the caregiver's moral urge. This awakening is itself an embodied experience, "a visceral tug to be *mindful* of this woman [parent, patient] within her actual, concrete circumstances and compelling vulnerability" (p.270, italics original, brackets added). Vulnerable, the parent calls (demands) us to step into relationship with her, to create a relational space where practitioner and parent can be together. *Demand* comes from the Latin "to entrust" (Merriam-Webster online) and its root *mandere* (Harper, 2001, online etymology dictionary) means "to give into one's hands". Bergum (2007) says that "the word *demand* then becomes a moral word that points to our relational moral root—the commitment that we have to one another" (p.5). Recognizing both the embodied nature of vulnerability as experienced by these parents in the NICU, as well as the embodied response of the caregiver, reminds us that our commitment to the parents calls for more than explaining the technical aspects of care, the scientific realities of illness, even the practical orientation to the unit. We are called, through the vulnerability of the other, to engage with him. The nurse looking after Christine's baby that day was compelled by Christine's vulnerability and, through her actions, she stepped forward into relationship. As Christine described months later, the memory of this encounter and this nurse endures. Still we might ask: What happened here? It may be that something profound happened that day at the bedside, and may happen (or not) countless times a day in health care: the nurse and Christine experienced a moment of shared humanity and were made aware of the possibilities inherent in themselves. The nurse understood and responded to Christine and, by truly caring for her, the nurse became aware of her own vulnerability, her fragility and dependency. Hoffmaster says, "That is what vulnerability means for us" (p.45). This exploration of vulnerability in the NICU leads us into a consideration of trust, which both mitigates and intensifies the vulnerability of parents.

Trust

How does trust happen in the NICU? I wondered as I reflected on the parents' words of trust and my own experience as nurse. What does it mean to trust; to be trusted? Why does trusting, and being able to trust, matter? How does trust, or its lack, affect a relationship? What responsibility do health care practitioners have to be trustworthy, to foster a parent's trust? This research does not necessarily answer these questions, but their provocation helps us to begin thinking about trust in the NICU. Clearly, as described by the parents, trust influences their entire experience. A physician and ethicist who was written extensively on trust as the basis of morality in the practice of medicine, Edmund Pellegrino contends that "trust is ineradicable in human relationships" (1991, p.69). Yet, he goes on to say that even still, it has also always been problematic, particularly when we are vulnerable: sick, young, old. Knud Løgstrup, a Dutch philosopher, places trust at the root of humanity, suggesting that trust is a fundamental part of being human, and maintaining that it is the trust offered from one person to another that drives the essential ethical relationships we have with others in the world: "Through the trust which a person either shows or asks of another person, he or she surrenders something of his or her life to that person" (1997, p.17). Although Løgstrup was not referring to a concrete part of life here, it is hard not to be struck by the image of the parents in this study surrendering their baby to the practitioners in the NICU. By this basically forced action (they have no other choice); they ask the practitioners in the NICU to be trustworthy, and to trust them, as parents. It will be no surprise to any reader that trust was so important to the parents of this study, or to any patients and their families. We all know, by virtue of living in the world with others, how important trust is in our lives and relationships.

Let us consider trust while again recalling the evolutionary quality of the parents' experience of the NICU environment. Thorne and Robinson (1989) conducted a multiphase, qualitative study of relationships in health care from the perspective of chronically ill patients and families. The researchers found that the families progressed through stages in the development of their relationships, based around a core variable of "reconstructed trust." The first stage is naïve trust, a time when patients and families believe that health practitioners will act in their best interest, keep them fully informed and include them in decision making. Inevitably, the families become disenchanted (second stage) and angry as they realize that health professionals do not necessarily have the same goals that they do. Eventually a guarded alliance (third stage) might be established as families remain involved with their ill family member, become more informed and learn ways to be with the health practitioners, such as knowing what questions to ask and identifying who treats their relative with compassion. The researchers describe different ways families may come to the stage of guarded alliance through different ways of reconstructing trust. Trust is reconstructed when families and patients trust both the health professionals and their own competence; and occurs in different configurations.

Thompson, Hupcey and Clark (2003) studied the development of trust between parents of hospitalized children and nurses using the grounded theory method. The core variable identified in the study was meeting expectations. The researchers report the parents were constantly assessing whether their expectations for care had been met during interactions with the staffing hospitalization. When expectations were met, the parents were seen to have "general trust", if expectations were exceeded, "global trust", and if expectations not met, the parents "distrusted". Trusting behaviours were related to building rapport and caring, while uncaring behaviours inhibited the development of trust. The vigilance of parents was evident in all three of these trajectories. It seems, trusting or not, parents were always watching for the best care to be provided to their child. The definition of trust used for this study lacks the richness and inherently relational intention when compared to Løgstrup's thoughts on trust above: "trust is the dependence on another person based on the congruence between the expected and actual behaviours of the trusted person" (p. 137).

Still, both of these studies resonate with the experiences of the parents in this present research in some important ways. We see that other researchers have encountered the fluid, transitional nature of the experience, as the parents are reassessing trust as they encounter the practitioners caring for their baby. I remember here Jamie McDonald's words *you observe because you're there fourteen hours a day, watching*. Upon entering the NICU, they describe being so grateful that this service existed for their baby and acknowledged that without it, their baby would die; we can recall Ivan Delich's immediate feelings of relief and confidence that everything would be fine. As they became more familiar with the unit and their child, there were events that angered and worried them, such as being excluded from rounds and from the opportunity to provide care to their babies. They also are struggling to become parents to their baby and coming to trust (or not) the nurses and other practitioners strongly influences this development. For the families in this study, especially the five who had long stays, by the time of discharge they described knowing how to navigate the NICU in a better way with increased confidence in their roles as parents, even while they all remain vigilant of their baby's care. Speaking of trust like this, as a process that peaks and wanes, we must be careful not to become overly complacent and forget the profound words that began this section. Trust is inherent to being human. As the parents surrender their babies to practitioners and we strive for trusting relations, we do well to remember what Govier (1998) notes in *Dilemmas of Trust* "the second dilemma is that trust, an essential element in all satisfying relationships, is a fragile thing, easier to break than to build" (p.204). If we discover we have been let down by someone we trust, do we not ask ourselves: can we ever trust this person in the same way again?

Responding to Parents' Call to Be Seen

Throughout both the interviews and the experience of reading the transcripts, I became aware over and over of a nonverbal and subtextual meaning being expressed by the parents. Occasionally, it was explicitly stated, but either way, needing to be recognized as people was a strong element of the parents' experience. In some ways, it can be seen as weaving through the other themes, asking to be seen while becoming a parent in the unit, asking that one's vulnerability not go unnoticed, and asking to trust and be trusted.. Attention to this theme seems to raise another question: How can NICU practitioners see the babies and parents in their care? Why should they? Bergum and Dossetor suggest that

> If individuals are treated as nonpersons, there is a danger that they may be treated as objects. And when one treats another person as an object, then real danger is seen: everyone may become an object. In treating others as objects, we all lose subjectivity and lose our moral capacity to affect and be affected by the other" (p.144).

It may seem that I am advocating for practitioners in the NICU to regard and recognize parents of the babies in their care as people, and of course, I am. But what can never be lost is that this recognition is important not only for the sake of the parents, but because when one person regards another as something less than a person, harm is done to both people and the risk is run of irretrievably losing an element of our humanity. "When humans find themselves surrounded by nothing but objects, the result is loneliness, and, as Ken Wilber worried, this vast loneliness 'has soaked into every strata of our society'"(p.144). If this is true, if regarding each other as objects poses this high risk, then perhaps we can also learn that when we do treat others as persons and they us, that is when our real potential as human beings is evident and can flourish. To start this conversation, I look at relational autonomy as an idea that practitioners can use to frame their experience with parents, and follow this by discussing two specific topics brought to this study by the parents: the 'prognosis talk' and primary nursing.

Relational Autonomy

The inspiration for relational ethics came, in part, as a result of "puzzling about the notion of autonomy" found to be so prevalent in the bioethics literature (Bergum & Dossetor, 2005, p.xv). Beauchamp and Childress (2001), authors of the four principle approach to bioethics, include *respect for autonomy* as one principle. Acknowledging the risk here of oversimplifying this concept, in Western societies autonomy is generally taken to mean a focus on the freedom of will of independent, rational agents (Atkins, 2006; Beauchamp & Childress, 2001; Fishbane, 2001), and is dependent on an asocial, abstract conception of individuals (Donchin, 2001). Immediately, as an NICU nurse, an obvious difficulty with this conception of autonomy presents for those who clearly are not autonomous, for example, infants or seriously ill adults. But even thinking about this disembodied understanding of autonomy for healthy, competent adults, it is hard to relate to *being* autonomous in real life, particularly after becoming a parent. It is hard to even imagine a decision made without the influence of others and without in turn considering the effects of the decision on others. Beauchamp and Childress's concept of autonomy seems to set us apart from one another.

Instead of independence, relational autonomy acknowledges people as *interdependent*. "A person, as an interdependent being, is both separate from others (independent) and connected to others (dependent) at the same time" (Bergum & Dossetor, 2005, p.79). Bergum and Dossetor's conception of relational autonomy is grounded in mutual respect. Respect is crucial for any relationship, and mutual relationship emphasizes being respectful to oneself and others, and therefore includes respect from others. Mutual respect demands that we acknowledge and value the ways that we are different. Anne Dochin (2001) tells us that autonomy does capture values important to ethical theory, but only if severed from individualistic assumptions. "Crucial to the reformulation of autonomy is a positive conception of human agency that recognizes relational experiences as an integral dimension of individuality" (p.367). Of course, each of us travels through life, in an existential sense, alone. But we also come to know ourselves through others. Relational autonomy is active, evolving, rather than a state that is either achieved or not achieved (Bergum & Dossetor, 2005).

For health practitioners caring for babies and parents in the NICU, attending to autonomy as something to foster, rather than something to achieve (Bergum & Dossetor, 2005) makes room for the parents not only to make decisions with and for their babies, but also to rely on the practitioners. For how can they not become more dependent when their child is in the NICU? "Intensification of dependency is a normal concomitant of illness" (Donchin, 2001, p.375) and by extension, illness of one's child. Of course, the real risk that this dependence may be taken advantage of must always be attended to. But the autonomy of parents can be fostered as the situated social beings that they are, while not undermining their independence. Moving to understanding autonomy as a dynamic and relational concept calls for a broad shift in how bioethics is understood in academia and at the bedside. This fundamental change in how practitioners see parents, and also in how they see themselves, supports the practitioners and parents seeing *each other* as people. In the light shed by considering autonomy as a relational, nurturing concept, let us reflect on two particularly difficult moments shared by the parents in this research.

Telling Bad News

The parents in this study spoke of the discussions with NICU physicians about the condition and prognosis of their baby. They remember them as exceptionally difficult conversations and I wondered if sometimes as health practitioners our need to make sure parents know everything (for a multitude of reasons) prevents us from attending to each parent as an individual. In his memoir *At the Will of the Body,* sociologist Arthur W. Frank tells of his experience being diagnosed with and treated for testicular cancer. His regular physician does not detect the cancer, even after months of pain and a palpable lump in his left testicle. He is again misdiagnosed during a trip to the emergency with intense back pain, when he recalls no physical exam at all, only a reliance on the results of blood tests. Finally, in response to the back pain, his physician refers him to a sports physician who also happens to be an internist. After a complete exam, this physician suggested that he may have cancer. Even though this is a devastating thing to hear, Frank reports that he felt some relief at having his experience of his body validated. "Being told that you have cancer does not have to be devastating. Even though my worst fears were realized in what he said, the physician showed, just by the way he looked at me and a couple of phrases he used, that he shared in the seriousness of my situation. The vitality of his support was as personal as it was professional. Physicians I encountered later were optimistic about my diagnosis and prognosis; he was almost alone in expressing optimism about me, not as a case but as a person" (1991, p. 26). In contrast, several days later he has an abdominal ultrasound performed. Following the test, the radiologist confirms the diagnosis of cancer made previously by the sports physician. He tells Frank that he observed "massive" lymph nodes behind his stomach. When Frank asks what caused this, "he abruptly told me it was either a primary or a secondary tumor. Either the nodes were malignant in themselves, or their growth was a development from a malignant tumor elsewhere" (p.27). Frank describes his internal reaction later in the book, when he writes that after the ultrasound the physician said "'This will have to be investigated.' Hearing this phrase, I was both relieved and offended. The relief was that someone was assuming part of the burden of worrying about what was happening to me. But I was also offended by his language, which made my body into medicine's field of investigation. 'I' had become medicine's 'this'" (p.51). Frank (1991) compares the feelings he experienced leaving both physicians – the first feeling that his pain was being taken seriously and that he was supported, and the second feeling the reality of cancer and completely alone.

Such experiences of being told bad news provide some insight into what might make the experience more meaningful and less *brutal* (Ivan Delich) for parents in the NICU. We might ask why some physicians are able to do this. In the language of relational ethics, why is the sports physician able to engage and be respectful when the other is not? Neither physician knew Frank before these visits, why was one able to engage and one not? How did it happen that one of these physicians connected with Frank, and was able to share this experience by virtue of their shared humanity? Is it that he saw the person in front of him, facing a profound diagnosis rather than primarily his test results which revealed the diagnosis? How did he *do* this differently? Does the first doctor do it with all (most) of his patients? Finding words to describe what happens in situations like this in order to emulate or teach are difficult. They falter and seem inadequate to describe the subtleties and nuances that are relational practice. I suggest next that the parents in this study see primary nursing as being one possible way to support practitioners and families coming towards each other in the NICU.

Primary Engagement

During my tenure as a nurse in the NICU, primary nursing happened very much as the parents here have described it. Primary nursing refers to a commitment on the part of a nurse or several nurses, sometimes with the inclusion of physicians or other health practitioners. The process for creating a primary team was somewhat ad hoc, relying on sign up sheets and word of mouth. As an NICU nurse, I felt strongly that primary nursing was best for patient and family care, as well as for nursing practice. I present these biases in the spirit of disclosure that is relevant to this inquiry.

Primary care as a model of care is generally regarded as being developed in the United States in the late sixties by Marie Manthey (Pontin, 1999; Rigby, Leach & Greasley, 2001). Primary care is described on Manthey's company website as a "therapeutic relationship" between an RN and an individual patient and his or her family that "is initiated by the nurse and is in effect for the length of the patient's stay in a service or unit." (Creative Health Care Management, 2006). The nurse identifies needs and priorities and communicates them to the healthcare team with a focus on the nurse-patient relationship. Accountability for care is clear and the patient and family are included in planning care.

The nursing literature reports some disagreement on the outcomes associated with primary care, in terms of outcome measures such as quality of care, nursing satisfaction, nursing retention and cost. There seemed to be less disagreement in terms of patient and family satisfaction. In general, researchers and authors agree that further research using sound methodology is needed (Drach-Zahavy, 2004; Gardner, 1991; Gardner & Tilbury, 1991; Rigby, Leach & Greasley, 2001)[8]. Some authors report similar results as experienced by the parents in this study, that is, primary nursing can be difficult for the nurse. The nurse participants in Goode and Rowe's (2001) study of primary nursing (in an adult intensive care unit) perceived primary nursing as positive for the patient and family as it supported the development of relationships with them. The nurses also felt that primary nursing presented some disadvantages. These consisted mainly of increased stress caused by working with "difficult" patients or families and from nursing one patient over an extended period of time. Rigby, Leach & Greasley (2001) were surprised by finding a reduction in nurses' satisfaction with their role after a change to primary care. They suggest the dissatisfaction may be explained in part as a reaction to the change itself, since the nurses did not make the decision to change to a primary nursing structure. In the evaluation of a thoughtful and well-planned change to primary care in an NICU in Ontario, Canada, parents, in particular, expressed satisfaction with the change (Alcock, Lawrence, Goodman, Ellis, 1993). However, nurses' positive perceptions of their work environment, including autonomy, decreased. These authors report that supervisory staff had difficulty adjusting to the new roles and that education for supervisors as well as nursing staff is ongoing. Drach-Zahavy (2004) suggests that supportive management is needed to fully make use of the benefit of primary nursing.

The parents in the current study clearly described their primary nurses as contributing profoundly to their baby's admission and, indeed, their life. The relationships were rich and complex; those who did not have a primary nurse acknowledged the benefits and some quite obviously longed to have a primary team. Although the literature on primary care remains undecided about its benefits, it is more clearly positive when reporting patient and family satisfaction. The current primary care assignment system in NICU, as described by the parents, is so arbitrary it can almost be considered harmful to the parents. It was quite evident from the parents in this study that they "felt rejected" when their request for a primary team went unanswered. It is a worry that even when a primary team is created successfully this may cause harm, as the inequitable nature of the system is emphasized to the parents who did not receive primary nurses.

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[8] For a more complete review of the literature on primary nursing, see, for example, Goode & Rowe (2001) and Sellick, Russell & Beckmann (2003).

From the perspective of this research, that is, attending to the moral nature of relationships between NICU parents and practitioners, we can see primary nursing in a slightly different light. The nurses in this study, as reported by the parent participants, explained that primary nursing could be very difficult, demanding and emotionally taxing. This seems to be reasonably confirmed by reports in the literature. Bergum and Dossetor (2005) suggest that the common worry in healthcare is that of over-involvement, becoming too close to one's patient and losing oneself. However, they challenge us to be equally concerned when healthcare practitioners are under-involved with those in their care. Relational engagement is a way to understand the connection between patients, families and healthcare practitioners. Practitioners are those committed to responding to the person in care and "through the experience of responsiveness to the needs of the other, the caregiver discovers and responds to the moral commitment of relationship" (p.110).

If we recognize vulnerability as a force calling us to be moral, then engagement can be seen as our answer to this call. Bauman says that "…it is precisely that weakness of the Other that lays bare my strength, my ability to act, as responsibility. Moral action is what follows that responsibility" (1993, p.124). Bergum and Dossetor (2005) address the nurses' worries about losing themselves in the emotional drain that they identify with primary nursing. They agree that "the fear of depletion is powerfully debilitating" (p.113). Being open to those in your care does not have to mean that everything (emotions, self) falls out through the openness. Rather, being open to giving means being also open to receiving, to being replenished. If we are unavailable to others, we are therefore unable to be replenished by interaction with them. "To be engaged means that one responds to the needs of others. In this moral response, one does not lose oneself, instead, it could be said that one gains one's self—finds out what one is capable of" (Bergum & Dossetor, 2005, p.111). I suggest that primary nursing can provide structure for supporting engagement in the NICU. Of course, this does not mean that relational engagement will be automatic for primary nurses or impossible outside of a primary nurse relationship. But supporting a culture of relationship-based nursing can enable nurses, babies and parents to be well situated for moral engagement.

Implications for Clinical Practice

In essence, this research attends to the moral importance of the relationships between parents and practitioners in the NICU. How can research that seeks such an end contribute in a helpful way to current practice? This research provides practitioners with the opportunity to consider their own practice. Although I have presented no lists, or "ten ways to be moral", instead I suggest that practitioners consider their own implied promise to respond to every individual parent. The intent was to move practitioners towards understanding these relationships as important not only in terms of providing competent technical care or even in terms of providing gentle, empathetic care, but in terms of recognizing and nurturing a moral commitment. Practitioners can reflect on their own contribution, their own possibilities within these relationships, within the relational space. Even the beginning practitioner can be conscious of and open to the importance of contributing to an interdependent environment and entering relationships as a conscious moral choice. Zygmunt Bauman (1993) suggests "that what makes the moral self is the urge to do, not the knowledge of what is to be done" (p.80).

Suggestions for Further Study

The questions I ask here arose during my clinical practice as a NICU nurse. The curiosity and reflection that germinated during my clinical experiences, as mentioned, was made pressing largely by my own experience of becoming a mother. Thus, I chose first to explore the relationships between parents and practitioners from the parents' point of view. A clear next step for study would be to seek the point of view of the practitioner by asking them about their experience of these relationships. A study such as this could include a component of participant observation to supplement interviews as a way of learning about the relationships. Also, the findings from this study point to a need to further explore primary care nursing, to further explore what seems to be a disconnect between what the parents feel is important and what the nurses are willing to volunteer for. A study such as this could include an interpretive description of primary nursing, from both parents' and nurses' points of view, but that also includes nurses who do not choose to primary. Further, a study could be undertaken to explore re-framing the primary care process. A study such as this might attempt to understand what it is that makes primary nursing unpalatable to many nurses and, with this insight, develop a primary nursing model that meets the needs of babies, parents and nurses in the NICU. Other questions to consider regarding relational ethics: what is the relation of mutual respect and engagement to each other? Can one be present without the other? (This question comes to mind when I consider the parents who did not like the nurse themselves but did recognize and respect the care they gave their babies.) In fact, does this matter? Am I being too concerned with the theoretical part of relational ethics, does it matter clinically in practice? It seems there is rich opportunity to further understand the moral relationships in the NICU as well as to further explore relational ethics.

Conclusions

This inquiry has been focused on revealing the moral nature of relationships between parents whose babies are hospitalized in the NICU and the health practitioners who care for them. I sought to understand these relationships from the point of view of the parents who had lived through them. Their descriptions have evoked four themes centering on their impression of the neonatal unit, their experience of being vulnerable and vigilant as parents, the broad influence of trust in the NICU and their deep desire to be recognized as people. The evolutionary nature of the parents' perceptions of the NICU has been discussed. It is suggested that the powerlessness of the parents' vulnerability, paradoxically, has a power of its own: that of calling the healthcare practitioner to relation. I have recognized trust as complex and fragile, but fundamental to relationships between healthcare practitioners and those in their care as an essential part of and link to our humanity. As a way toward answering the parents' call to be seen as people, I have discussed the notion of relational autonomy as a way for practitioners and parents to know each other and considered this using two examples raised by the parents: hearing news of their babies' prognoses and primary nursing.

The parents' descriptions of their experiences have profoundly moved my thinking. Specifically, I recall the introduction to this text, written in large part long ago during the planning stages of this project. I refer to ethical dilemmas, those 'classical' ethical issues such as discontinuing care and resource allocation that tend to receive most of the ethical attention in healthcare, as moral mountains. I then state my explicit interest in the broader moral landscape of relationships and everyday care, as composed of conversations, touches and gazes between people. As I reflect on this now, I need to ask if my own purposeful focus away from the 'big' moral issues also does injustice to a more wholistic way of thinking about morality in the NICU and healthcare in general? I worry, too, that I have occasionally used misleading language in this text when refering to morality as a dimension of these relationships. This is not meant to suggest that there is a moral dimension to these relationships in the sense that there are also other dimensions that are not moral. We are inherently moral creatures. Morality exists before, and is foundational to, the scientific and artful aspects of practice. The moral commitment exists whether it is described that way or not, whether it is attended to or not.

In sum, I still contend the broad moral landscape of the NICU is what demands our attention. Of course, the moral landscape includes the moral mountains. It is varied and complex; the landscape around us includes *everything,* from horizon to horizon. This is made vivid when considering the NICU baby. Although my intention was to better understand the relationships between the adults in the NICU, the baby was clearly central to the parents' experience. The baby's well-being and the process of becoming a parent to this baby (whether first time parents or not) embody these relationships, the baby gives them life. The importance of understanding these relationships as morally inhabited lies partly with the baby herself; the initial experiences of parenting can stay with the parents forever and contribute to the foundation of the parent child-relationship.

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APPENDIX A
INFORMATION LETTER

University of Alberta

PROJECT TITLE:	Relational Ethics in the NICU: The Perspective of Parents
RESEARCHER:	Ms. Gillian Lemermeyer, Masters of Nursing Student (780) 492-4778
SUPERVISOR:	Dr. Wendy J. Austin, Professor, Faculty of Nursing (780) 492-5250

The purpose of this research is to help nurses and doctors understand what it is like for parents to have a baby in the Neonatal Intensive Care Unit (NICU). I would like to ask you for your point-of-view. You may choose to volunteer for this study. This research is being done for a master's thesis.

I will meet with you one or two times. I will tape-record our conversation, which will be 1 to 2 hours long. I want to hear what it was like for you when your baby was in the NICU. I am interested in your relationships with the doctors and nurses and other staff. The time and place of the interview will be convenient for you and me.

There are probably no direct benefits for you or your child from this study. You will have the opportunity to tell your story and that may be valuable for you. Speaking of this time in your life may be difficult. We can take a break or postpone the interview whenever you choose. I hope that other parents of babies in the NICU will benefit from what we learn from you. You can stop the interview at any time. You may refuse to answer any question and you are always free to withdraw from the study. I would be happy to give you a report of the findings when I am finished the study.

All information will be kept private, except when professional codes of ethics or the law requires reporting. The information you provide will be kept for at least five years after the study is done, in a locked filing cabinet in Dr. Austin's office. Your name or any other identifying information will not be attached to the information you gave. Your name will also never be used in any presentations or publications of the study results. I will discuss the interviews with my research committee only. The information gathered for this study may be looked at again in the future to help us answer other study questions. If so, the ethics board will first review the study to ensure the information is used ethically.

You may contact Ms. Lemermeyer or Dr. Austin iff you have any questions or concerns about the study. Or, if you have concerns about any part of this study, you may contact the Patient Concerns Office of the Capital Health Region at 407.1040. This office has no affiliation with study investigators.

APPENDIX B
GUIDE FOR INTERVIEW QUESTIONS

Guide for Interview Questions

Initial Questions:

1. What was it like to have a baby in the NICU?
2. What were your relationships with NICU care providers like?
3. Are there any contacts or moments you shared with health care providers that stand out in your mind? Can you describe them?
4. Can you describe moments where staff made a difference to you, either in a positive or negative way?
5. What do you wish had been different about your relationships with staff?
6. What advice would you give to doctors and nurses about how to take care of families like yours?

To further explore:

1. If they refer to a positive or negative "connection" with a staff member…What was that (the connection, or lacking a connection) like?
2. Tell me more about…
3. What was that like?
4. Can you give me an example?

APPENDIX C
CONSENT FORM

University of Alberta
Consent Form

PROJECT TITLE: Relational Ethics in the NICU: The Perspective of Parents

INVESTIGATOR: Ms. Gillian Lemermeyer,
Masters of Nursing Student (780) 492-4778
SUPERVISOR: Dr. Wendy J. Austin,
Professor, Faculty of Nursing (780) 492-5250

Do you understand that you have been asked to be in a research study?	Yes	No
Have you read and received a copy of the attached Information Letter?	Yes	No
Do you understand the benefits and risks involved in taking part in this research study?	Yes	No
Have you had an opportunity to ask questions and discuss this study?	Yes	No
Do you understand that you are free to refuse to participate or withdraw from the study at any time? You do not have to give a reason and it will not affect you or your child's care.	Yes	No
Do you understand there is a possibility that the discussion may shift toward topics you find upsetting?	Yes	No
Has the issue of anonymity and confidentiality been explained to you?	Yes	No
Do you understand that the interview data you provide for this study may be analyzed in future studies?	Yes	No
Would you like a report of the research findings sent to you when the study is done? If so, Address:	Yes	No

This study was explained to me by: ______________________ Date:________

I agree to take part in this study.

______________________________ ______________________________
Signature of Research Participant **Witness (if available)**

______________________________ ______________________________
Printed Name **Printed Name**

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

______________________________ ______________________________
Signature of Researcher **Printed Name**